UNIVERSITY OF OSLO
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My Health Book

Designing a patient controlled system for gathering, organizing and using health data

Master thesis

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Abstract

Background: Many e-health initiatives are focused on patient *centered* IS, but there is less focus on patient *controlled* IS. My Health Book is a initiative that challenges the notion that the health providers should be the carriers of health data, and that the patient should play only a peripheral role in the information flow pertaining their care. *Objective*: To derive guidelines for designing a patient controlled health information system that can gather, organize and use patient data. *Methodology*: Action design research is employed in two iterations to derive guidelines in a patient- patient health data ensemble. *Method*: Create a prototype that provides functionality for storing and sharing personal patient records using a web system and an iPhone app. The app is used to take snapshots of printouts from a health care provider, and is stored in 5 pre-set immutable categories, which can be accessed online, displayed at a consultation, or shared remotely using a one time code system. Evaluation is conducted on the prototype in two stages, first by means of a workshop, second by focused interviews with test users. *Results*: Support is found for using existing output channels from the Norwegian health information infrastructure in the form of paper printouts, appropriated by the app and mobile phone camera. Adversely, the idea of remotely sharing health documents organized in a patient controlled solution has met resistance and has proved to be problematic. Patient control is identified as being dependant on empowering technical abilities. Targeting the IS towards two audiences with conflicting interests negate control through the introduction of tensions that manifest in the technical implementation. Three design guidelines are produced for the role, implementation and look & feel of patient controlled systems.

Contents

Chapter 1

Introduction

This is an action design study (Sein et al., 2011) that through designing and testing a high-fidelity (Rudd et al., 1996), high-resolution (Houde and Hill, 1997) prototype seeks to derive design guidelines for the creation of patient-controlled systems. My Health Book differs from other studies on patient involvement through information systems (IS) by positioning itself as patient controlled, not just patient centred. Through this study the evolution of a the design for a system that is purposed towards letting patients gather, organize, use and share their medical data will emerge.

A desire to learn about the implications of what the term patient controlled means for designing an IS was the main reason for the execution of the project. Three dimensions of patient controlled systems are investigated through design in this thesis. These are role, implementation and look & feel. The role of a patient controlled system, how it can be implemented to fulfil the identified role, and how the implementation can be given a look & feel that is in harmony with the envisioned role.

The IS that is designed in the project takes the form of a service oriented platform, consisting of a shared service layer, a web site, and iPhone app. The systems are designed to store health data that can be readily acquired as printouts from a health organization, such as general practitioners, hospitals and private labs. Paper is applied as a low-tech gateway (Hanseth, 2001) into the large health information infrastructures (II) that already exist today, and that are maintained and produced by the established health organizations. Paper journals are imported by the patient into My Health

Book via a camera feature in the app, or by using a scanner and the website.

Appropriating patient data through paper in a patient controlled system reveals several interesting questions and problems, many of which are partially answered by other studies. Wibe et al. (2011) studied Norwegians that were given insight into their health data, and identified that the insight gave a sense of control, prompted a desire to take responsibility for information flow, having the ability (and executing it) to examine the accuracy of the record, feeling misrepresented, feeling misjudged and as a means of acquiring more knowledge. The possibilities that this study identified can be realized through IS design, whilst the challenges identified can lead to both exacerbation or harmonization of issues around mistrust and misrepresentation.

Effects of patient centeredness have been demonstrated to provide value through patients ability to exert control over their situation and how it is communicated to health workers, so that she can be better taken care of from a holistic point of view, and not just as a symptom in a body (Snyder et al., 2011). Patient controlled as a term is posited on moving away from a paternalistic way of conducting medicine and towards a holistic one, but it must do so without foregoing the aim of reaching a common ground between patient and doctor (Wagner et al., 2005).

1.1 Project background, my position and our motivational rationale

The project was started in late spring of 2012. The original idea of My Health Book was brought to the institute of informatics at the university of Oslo by a doctor (anonymized), who for a long time had recognized the problem of poor access to relevant medical data and having to rely on patients' second hand accounts. He wanted to know if the patient could become the carrier of his or her medical data, so that the many problems of communication within the health organizations could be bypassed. If the idea proved to be viable, then the doctor would assume to role of an entrepreneur, so that the project could be commercialized. It was from these notions and original plans that the idea of MHB evolved. The full

account of the evolution will be presented in chapter 5.

A project group was established, consisting of the entrepreneur doctor, one lecturer, one professor (my supervisor), a PhD student, and another master student. The project was managed by my supervisor on behalf of IFI. The lecturer took on the role of general consultancy, especially providing very knowledgeable insight into matters concerning privacy. The PhD student, with a degree in law, provided aid on legal questions, and authored the EULA for My Health Book. A second master student joined the group at a later point, and provided knowledge and input on compliance and interfacing with the health sector in general, from which he had over 20 years experience.

The last member of the group was myself. I was originally hired to design and develop a high-fidelity prototype (Rudd et al., 1996) at the beginning of the project, when the group consisted of just the entrepreneur doctor, my (soon to be) supervisor and I. At that time my role in the project was only that of hired help to aid in development, and it was only after some time spent developing that we agreed that I should write my master thesis on the project.

1.1.1 Motivation for research

The My Health Book project proposed to create a novel artefact that would adopt as of yet unexplored means of gathering, organizing and using health data, under a mantra of simplicity that was in opposition with the established ways of designing and building similar classes of systems. The promise of an IS that provides novel utility and value through bypassing technical complexities of information infrastructures, using paper as a low-tech gateway, was worthy of exploration for several reasons.

Paper printouts were the first of these reasons. All health institutions, be it GPs, hospitals or private labs, offers the ability for the patient to take home a copy of any or all health data produced for them. The data stored on the paper printout exists in digital form in an II that has a very hard time with coordinating the transport of said data between institutions. Could, and would, the patient become her own data carrier provided with the right tools? And what would the right tool be?

The second reason was the complex socio-technical arena that My Health Book would have to navigate and negotiate. The data on the paper printouts are created within the context of health institutions, and the intended usage of the data is within the boundaries of these institutions. Can this data in unison with the promised utility of an IS that labels itself as patient control be realised as something that gives value to the patients? Also, as the IS would purpose itself towards two target audiences, patients and health personnel, what and how could control be exerted by the patient, and over what exactly?

Many interesting questions came from the envisioned role and implementation of the system that had, in the context of a privatized initiative with paper as the data carrier, not yet been explored elsewhere. The motivation for the research was to better understand how a patient-controlled system could create value from the many and complex socio-technical elements that it interacted with, what kind of challenges would arise, and how these could be met with the design of an IS.

1.2 Prototype design as a method of inquiry

To learn about the concept as it was proposed it was decided that a prototype should be built. The immediate question that arises when thinking about building a prototype for this purpose is "what do prototypes prototype"? Luckily, Houde and Hill (1997) has provided insight on this question with an article by the same name.

Houde and Hill (1997) points out that the definition of a prototype is subjective and subject to organizational interpretation. They argue that before we embark on any prototyping venture we should first agree on a vocabulary in order to settle on what it is that we want to achieve with the prototype, and which analytical properties are important. For this purpose they propose three dimensions of investigation. These are the role of the system, the implementation (nuts & bolts) of the system and the look and feel of the system.

Each of these dimensions has different purposes and serves to shed light on different elements of study. Houde and Hill (1997) argue that different

kinds of prototypes can be built to explore the three dimensions using different methods, even by building up to three prototypes in parallel using the cheapest means available to uncover knowledge about a particular dimension. Essentially, they argue that one prototype to investigate all dimensions at once can be costly and time consuming, and that three prototypes in parallel might be better in stead of aiming for a prototype that integrates all the dimensions from the beginning.

For instance, *If the role [of the prototype] is well understood, but the goal of the artefact is to present its functionality in a novel way, then prototyping must focus on how the artefact will look and feel. If the artefacts' functionality is to be based on a new technique, questions of how to implement the design may be the focus of prototyping efforts* (Houde and Hill, 1997, p. 1). However, because the only available manpower for the prototyping activity was myself, and we had limited capacity for conducting user tests, it was decided that we would create a prototype that would be suitable for exploring all the three prototype dimensions.

The three dimensions are affected and understood through different environments, contexts or theories in the study of MHB. The role dimension can be understood through patient empowerment theory. The implementation is understood through information infrastructure theory. The look & feel dimension is affected by interface design theory, in effect how the role and implementation is best harmonized and presented to the end user. In this respect, the applied theory is to be understood as input to the design process, and not necessarily as analytical tools only. The composition of prototype dimensions and theory is shown in table 1.1.

Two forms of evaluation arise from a prototyping activity. One is that of traditional feedback through user evaluation in interviews and workshops, the other is within the design team, and the teams' tacit knowledge acquired from effectuating the design. The latter acquired experiences are externalized (Von Krogh et al., 2000) through dialogue and group interaction, and through accounting in detail for the steps in the prototype evolution, so that the reader can gain insight not just into the final ensemble, but also the process leading up to it.

Prototype dimension	Mediating theory	Applied theory components
Role	Patient empowerment	Acknowledging and employing positive effects of patient centeredness, designing to avoid negative effects
Implementation	II theory	Gateways, tight couplings, complexity, installed base cultivation
Look & feel	Interface design theory	Web and app design principles, mental model, cognitive dissonance

Table 1.1: Composite alignment of prototype dimensions, theories.

1.3 Research question and methodological preamble

Action Design Research, ADR for short, has been chosen as the methodology for the project. Sharing many similarities with the design science (DS) methodology, ADR is an extension of DS that uses designing and building as research methods. Chapter 4 is devoted to the methodology, where it will be accounted for in much greater detail, but before arriving there some of its components must be briefly explained so that the research question can be better understood.

Each ADR cycle produces a new version of the artefact that is being designed. New knowledge can be derived from each cycle. In the ADR methodology, once the artefact is considered to be complete and no more iteration are to be done, the end result should be a set of design guidelines that explain how one can arrive at a similar solution, and that makes explicit the challenges one should expect along the way. The types of guidelines are general design principles, ensemble specific contributions, and user utility (Sein et al., 2011).

Aiming for guidelines as research output has constraining effects on the research questions that can be posed within the ADR methodology. Common to both design science and action design research is that the outcome of the research project should bea class of solutions for a class of problems. From this definition of ADR we are bound to also create a research question that adheres to this taxonomy, i.e. the research question

must pertain to a particular class of challenges that are broadly (i.e. class) applicable, and also solvable with the design and introduction of an artefact. In addition to this, the class of problems must exist within a certain domain or analytical unit. Thus, before I finally arrive at a research question, I must first define my analytical unit and its scope.

Integral to the methodology of ADR is the design iteration and the artefact, or ensemble. As the word ensemble perhaps hints towards, the analytical unit is a composition of several (socio-technical) elements. In our case the identified ensemble is the developed artefact and patient plus patient data assemblage (DeLanda, 2006). For clarity, the term ensemble is what defines the analytical unit of this thesis, and assemblage is used to denote the irreducible relationship between patients and patient data. As a socio-technical entity, the patient is not yet a patient unless he or she has been admitted to some form of care. Preceding this is the acquisition of the status of patient, which always comes with a piece of patient data. Inversely, patient record data will not exist if there was not for the patient. In this sense, the assemblage of patient plus patient record is non-reducible, and can thus constitute one part of the ADR ensemble. The other part of the ensemble is the design and effectuation of the MHB prototype.

An ADR ensemble is by its formal definition very close to an assemblage. As it is defined by Sein et al. (2011), the ensemble is a technical artefact inscribed with organizational structure, goals and conceptualizations. An artefact that is defined by its understanding in and of an organization becomes a valid unit of analysis when its meaning is reificated by those who inhabit the context (Wenger, 2006). In short, because MHB is a novel concept, presented to a group of users who has not been exposed to it before, the developed artefact must undergo negotiation towards what it should mean, so that it can solidify from a more fluent state . As the concept settles through negotiation and development, its boundaries become clearer. These boundaries define the border to exterior of the assemblage and the properties available for analysis in the ensemble. As boundaries become clearer, so do the challenges related to the ensemble.

This understanding of the elements that form the analytical unit within the ADR methodology defines the form that the research question can take.

The research has to be answerable within the boundaries of a high-fidelity (Rudd et al., 1996), high-resolution (Houde and Hill, 1997) prototype. The limitations are:

1. The research question must be of such a nature that the unit of analysis can be understood within the dimensions "role", "implementation" and "look & feel".

2. It must address a class of problems and propose an artefact that has redeeming qualities in the same scope, i.e. a class of solutions

Rule one is satisfied by power of the prototype; its physical manifestation allows for insight into look and feel, its testing by users allow for the discussion of its role, and its implementation explore its possible relations to information infrastructures. The prototype is further reified through the project teams interaction, and through the design activity and accompanied discussions the tacit knowledge produced through interaction can be externalized to shed light on the three dimensions. The second rule is be satisfied as classes of problems and constructed solutions to them emerge through the prototyping activity.

The research question that emerges from these rules and accompanied justification is;

> What are important design guidelines when designing and building a patient controlled IS for gathering, organizing, using and sharing medical data?

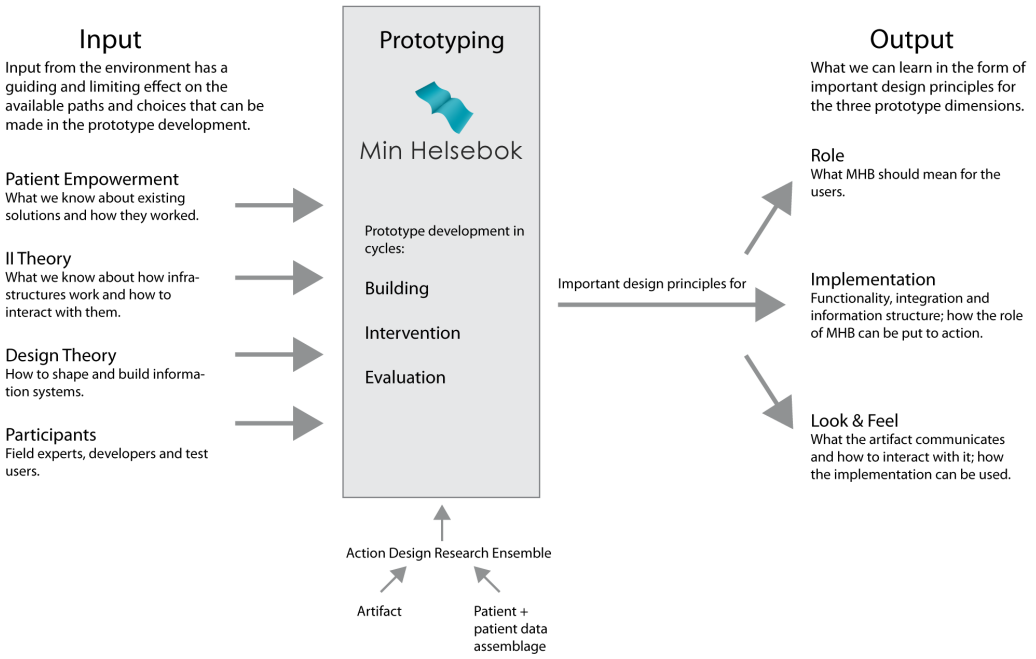

Figure 1.1: Research design.

Figure 1.1 provides a graphical representation of the research structure as it is described so far. In sum, moving from left to right, the project takes input from theory and environment, and uses this to guide the iterative design evolution of the envisioned artefact, from which the output is a set of design principles for the role, implementation and look & feel patient controlled systems.

Of course, defining the rules of the type of question one can pose, instead of posing a question and then defining its limitations, is uncommon, but the reason for this "order of business" is that MHB as a project was initiated as a design project prior to the formal definition of the research that would be executed around the design activity. It would be artificial to claim that I stated my research question prior to deciding that the question should be answered by designing something, because that is simply not the order in which the research happened. First it was decided that an artefact was to be built in order to learn something about a phenomena, but what that phenomena was did not present itself from the start. As such, the possible format of the question was constrained by the research activity, and that is the reason for this short methodological preamble prior to presenting the research question.

In the following chapter I will account for similar existing solutions, and how MHB contrasts with them. Following this I will account for the reasoning and theories that were used as input for the prototype development in chapter 3. I will continue with presenting the design methodology and it's applied methods in chapter 4 before I in chapter 5 will present the chronological evolution of the conceptualization and design of the My Health Book prototype through three stages. In the remaining chapters I will present my analysis (chapter 6), including a discussion, and finally a conclusion, including reflection on the process and suggestions for future research (chapter 7).

Chapter 2

Existing solutions / State of the Art

This chapter aims is to situate My Health Book in a context that can be used for comparison. This comparison is used to contrast features of MHB against other projects, acknowledging that most of MHB is not wholly unique. Knowledge from other projects can guide MHBs design choices and be used to identify what makes MHB novel in order to guarantee that the designs produced are research contributions and not routine designs based upon the application of well-known processes (Hevner, 2007, p. 90).

2.1 Closely resembling phenomena

2.1.1 My Health Record

The first project i will describe is My Health Record (MHR). The name is deceptively similar to My Health Book and is a project that has components that are seemingly identical to My Health Book (MHB) on the surface.

The case is covered in detail by Grisot et al. (2013) with an account of the systems features and development over time, portraying it as successful, largely due to their "under the radar" strategy for development. This strategy encompasses a course of action consisting of features such as reduced complexity (technical and organizational), bootstrapping (Skorve and Aanestad, 2010), and that infrastructural innovation has to happen *in*,

of, and on infrastructure in order to be successful (Grisot et al., 2013, p. 41).

In contrast to My Health Book, MHRs components are many and complex, and were originally envisioned with tight couplings to the existing health infrastructure. Today MHR consists of appointment booking, ordering of self-tests, secure messaging between health personnel and patients, deputy solution (assuming guardian role), ordering solutions (web shop) for treatment accessories, record of medicines, a Wikipedia network for patients, next of kin and health personnel registry, and specialized reporting forms from patients to clinicians (Grisot et al., 2013, p.12).

MHR also has MyDiary, a function that was designed to let patients enter notes into MHR both for personal use and to share with doctors. The difference between MyDiary and that MHB's core functionality of letting the patient input data is the data type that is allowed. MHB only allows images to be uploaded and has no option for providing any lengthy pieces of text besides the document title. MyDiary function did not make it into MHR as originally envisioned. A variation of the MyDiary module resurfaced in the next phase (2009-2012) with a specialized service for patients suffering from diabetes. This module allowed for patients to submit routine information prior to consultations (Grisot et al., 2013, p. 28).

A similarity between MyDiary and MHR is the ability to share with doctors. This was in part the reason why MyDiary did not make it as envisioned into MHR. It was stopped by the hospital privacy officer who was concerned that information input into this module could be put there in good belief that the doctors would read it. The mechanisms for sharing, and organizational routines, made no guarantee of this (Grisot et al., 2013). This is a challenge that also affects MHB, and which needs to be dealt with using mechanisms appropriate for the case and the context. MHR interprets the challenge of accounting for whether shares have been accessed or not to be one of patient-safety. However, this definition of the problem is produced not by the patient, but someone representing her. It is quite possible that the patient, using a patient-controlled system, might deem this to be a non-problem. A large difference between the system thus appears to be that in MHB the patient is in control of defining what the problems and challenges are, whilst public health institutions have representative

delegates for deciding what constitutes a problem or not.

MHR is situated in a different social and corporate context than MHB. While MHR must adhere to stringent official standards and procedures, MHB must not. The major implication of this distinction is that MHR comes across as a solution created and owned by a public institutions, with tight couplings towards other health II residing in the institutional domain. MHB intends to not come across as an IS that is tied into the organizational routines of public health institutions.

2.1.2 The memory stone

The memory stone is a Danish initiative that produced a physical artefact shaped like a rounded stone, essentially containing a memory stick, a wireless controller and a logic board. On it you can store a variety of information, such as *pictures, biomedical data, video* (Enquist and Tollmar, 2008, p.4). The prototype evaluation was conducted with pregnant women who had one of the same problems that MHB attempts to address; a means of consolidating health data in one place so that it can be brought to consultations by the patient. The memory stone was designed to replace an already existing pregnancy journal that the pregnant woman would have to keep up to date, and bring with her on consultations to both mid wife and physicians. This was portrayed as cumbersome and un-precise, as both mid wife and physicians often had to do redundant investigations and ask similar questions that could result in conflicting answers, which the pregnant women described as unsettling (Enquist and Tollmar, 2008) .

Connecting wirelessly to a Bluetooth transceiver, the stone can display many types of data formats on a monitor such as a computer screen or a TV, and be loaded with data via a computer interface using the same transceiver. Interaction with the stone in the display situation was done via gestures that were tracked with accelerometers built into the stone, similar to the Nintendo Wii (Enquist and Tollmar, 2008, p.6).

The findings in the evaluation of the memory stone were largely favourable. The researchers reported positive feedback reports on issues such as interaction and palpability, but more importantly they also found that the existence of such a device is warranted. For instance they

found that the modality of the technology, which required extensive interaction with the medical practitioner in order to load data onto the device, was in fact empowering. The physical transaction of data prompted questions that would explain the data they received, as opposed to simply synchronizing a medical journal onto a pre-fabricated account in a large public infrastructure that the public could access should they so please. This finding supports the case for MHB's transaction modality of using paper, as paper is acquired in the same context, and opens for the same possibilities of engaging with the instance that issues the data, e.g. through asking questions about the data they receive.

A core issue addressed was that of security. Many of the participants expressed concern that the data downloaded onto the device would suffer from degradation, or perhaps even get lost, even though they knew it was a verbatim copy of what the doctor had. They also inquired into the sensitivity of the device, and pointed out that it needed to be context sensitive. As many of the users had found it of value to include more than just the produced medical data, e.g. personal journals, they requested functionality that allowed you to exclude certain bits of data for certain scenarios. One such scenario was displaying of information to your spouse or family on a television set, where you might not want to accidentally expose your personal notes. Enquist and Tollmar (2008) was inconclusive as to whether or not patients as data carriers could be recommended.

2.1.3 Akteonline.de

Akteonline.de is a German initiative that is also very similar to the MHB project. Its main distinguishing feature is that it does not use paper as a transfer medium. It also incorporates some features that were considered for MHB, for instance emergency access. Ueckert et al. (2003, p. 100) presents the goals of akteonline.de as:

- to give citizens the possibility to be in charge of their own health record electronically,
- to provide access to this record through the Internet independent from place and time,

- to present personalized health information online and
- to serve as a medium for sharing selected areas of health information with caregivers (which in the end can be used as a communication between medical professionals, but under control of the concerned patient).

There is also a plethora of features of Akteonline.de that were not considered for MHB. In this sense the system differs vastly from MHB when it comes to the underlying philosophy of the system. MHB's philosophy is to keep things simple and only offer the necessities of functionality. For instance, Akteonline.de offers support functions for specific chronic conditions, such as diabetes, whilst MHB is disease non-specific.

It also offers categories for data organization. These are medications, outpatient data, journal, vaccinations, lab reports, and general medical information. In addition there are support functions such as a forum (e.g. self help), annotation features and practical information such as hospital data and address lists. In short, disregarding that akteonline.de does not use paper records for input, and that it has a vastly higher set of functions, it encompasses all of the functions planned in MHB.

Akteonline.de also supports two-way communication with healthcare providers. They achieved integration with the internal health information systems at the healthcare providers, and opened for letting doctors transfer data to patient accounts via xml. Transferred data was electronically signed by the transferring doctor, and the patient could not alter it, but she could delete it. Similar to MHB they also employed a one-time-access scheme using authentication codes, described as similar to that of a banking system (Ueckert et al., 2003, p. 102).

For the patients' perspective, the means of data entry into the system is analogous with MHB in the sense that they input data manually. Instead of using paper the patient inputs data into normal data fields. This implies a pre-set data structure for input data, a key discerning factor between akteonline.de and MHB.

Findings in the paper by Ueckert et al. (2003) are limited to inclinations towards positive empowerment of patients and that redundant medical tests were to some degree reduced.

2.2 Contrasting solutions

Table 2.1 presents the identified similar components of three other systems. Elements in the table are arranged in two categories. These are role and implementation, and correspond with the presented understanding of the prototype dimensions (Houde and Hill, 1997). Concept relates to the role of the system, whilst the other three rows, functionality, integration and information structure relate to the implementation of the concept.

Comparing the columns show that for the concept, MHB's philosophy is closest to Akteonline.de in the sense that they both allow for patient input of patient data that is produced by medical professionals. They are in contrast in the sense that the methods for doing so are different, i.e. MHB uses image representations of paper.

All other systems besides from MHB in the comparison are technically integrated with health information systems (HIS) in the public health infrastructure. Information structures in the different systems tend to be immutable, with the exception of the memory stone (Enquist and Tollmar, 2008), who has a degree of mutability in the sense that the user can form and load data of many types onto it, both medical data and personal health data, such as the diary. Comparing MHB with the immutable solutions show that a rigid information structure is not something that has been understood as a major hurdle, but in contrast with the other projects, MHB imposes a very broad structure, as opposed to a narrow, high-granularity model of data input.

Summarized, the novel aspect of MHB is that it is a solution that is similar to other empowerment initiatives, but in comparison it has a very narrow set of functionality, a novel way of gathering data, an immutable yet broad way of structuring data and is technically (digitally) disconnected from any other IIs.

	Minjournal	Mem.stone	Akteonline	MHB
Concept*	Owned by hospital, marketed as "info channel"	Physical device with usb/Bluetooth capabilities for carrying and sharing data	Patient in control, with input directly from existing HIS	Patient owned archive and sharing solution
Functionality	Broad function set, specific towards diseases, service integration, web site with BankID / Buypass authentication	Broad function set, rich data support, diary, physical artefact	Web site with very diverse functionality for specific diseases with high data granularity	Limited functionality, simplicity as mantra, camera
Integration	Tight digital integration with hospital IS	Proximity transmission of data from GP or PC , medium-tight digital integration	Tight digital integration with existing HIS	Paper-gateway, no technical integration
Information structure	Rigid, high granularity, can be adapted for different user groups	Mutable, "wireless USB-stick" as metaphor	Pre-set, but with high granularity, many input functions, e.g. diary, CT-scans etc.	Rigid, 5 categories, can not be edited , low granularity

Table 2.1: Comparison of reviewed similar solutions. Row marked * belongs to role category, others to implementation.

Chapter 3

Theoretical Foundations for Design Choices

The three prototype dimensions that are analysed are mediated by theory. In the introduction a table was presented that aligned each dimension with an input theory. To recapitulate, the dimensions were role, implementation and look & feel. Their input theories were patient empowerment, II theory and interface design theory.

Applying several theories and dimension will open for a more complete picture of the design and understanding of MHB, as it is the compound of the novel elements of MHB that make it distinctive. The remainder of this chapter will focus on theory that is relevant to the role and implementation of MHB, particularly II theory, health information infrastructure problems, and theories of patient interaction with IIs and their health data.

3.1 Designing information infrastructures

Hanseth and Henningson (2013) has contributed with descriptive theories of IIs, in addition to contributions of normative theory on how to design IIs. Hanseth and Lyytinen (2010, p. 1) defines information infrastructures as

> Shared, open, heterogeneous and evolving socio-technical system of Information Technology (IT) capabilities. IIs are recursively composed of other infrastructures, platforms,

applications and IT capabilities and controlled by emergent, distributed and episodic forms of control.

Within this definition it is clear that IIs consist of many capabilities, applications and platforms, and if one is make or change any of these components, then one is in fact building an II. In so doing it is important to adhere to well founded principles for how one expands an II. Hanseth and Lyytinen (2010) has proposes 5 II design principles:

1. Design initially for usefulness
2. Build upon existing installed base
3. Expand installed base by persuasive tactics to gain momentum
4. Make the design of IT capability as simple as possible
5. Modularize the II

Architecting IIs as a concept is not comparable with for instance the way an architect designs and executes the construction of a building. IIs are heterogeneous networks with limited central control, and cannot be designed in their full through top down design activities. The situations that many complex IIs find themselves in are the result of many failed "grand designs" (Bygstad and Hanseth, 2010).

Acknowledging that IIs are emergent rather than designed (Hanseth and Lyytinen, 2010) allow for a greatly different approach to designing with, for and in them through installed base cultivation implementation strategies, such as bootstrapping processes (Skorve and Aanestad, 2010, Aanestad and Jensen, 2011) that utilize IT capabilities in an II for immediate usefulness, expanding only when momentum has been gained.

Also, extending IIs do not necessarily mean that it has to subjugate the planned expansion by integrating it into the tight-couplings between the underlying technical capabilities of the II and the service delivery model (Tilson et al., 2010). New services can be derived through modular expansions, *allowing some components to be kept stable while others are changed without implications for the rest of the system* (Hanseth and Nielsen, 2007, p. 4). To achieve this one can employ the concept of a gateway, defined

as *technologies and standards applied across multiple communities of practice* (Edwards et al., 2007, p. 8), noting that paper adheres to this definition of a gateway. Gateways can be used to define the interface between two modular components, reducing inter-component complexity.

Regardless of how IIs evolve and grow they all become subject to path dependence (Edwards et al., 2007), a trait where that which came before defines future choices and options for how an II can expand. Over time the path dependence produces a stabilizing effect, a lock-in (Hanseth and Lyytinen, 2010) of IT capabilities in an II that hinder generative capacity unless the II can be "loosened up" through mechanisms that make it more flexible.

3.1.1 Health information infrastructures

Vikkelsø (2010) gives an account for 4 types of patient-centred information infrastructures. These are:

1. Shared care record systems,
2. Internet health sites
3. Online data access for patients
4. Electronic consultation systems

Healthcare is being split into sectors and institutions, causing problems of coordination and integration (Vikkelsø, 2010). This separation has prompted the influx of what Vikkelsø (2010) calls "shared care", where information technology is being used as a lever to facilitate for sharing of data between health II fragments. Four large problems arise in this climate of fragmented organizations and shared care:

1. The need for standardization of clinical records to accommodate storing in shared repositories
2. Ownership of data is unclear
3. Integrating with existing health care systems

4. Securing the privacy of patient data

Variation in taxonomies and different requirements for granularity is the cause of the standardization problem in point 1 and 3 (Vikkelsø, 2010). In MHB, the design choice of using paper as the transfer media is the envisioned solution to this problem, as paper has fixed granularity and no form requirements besides being stored somehow.

Local gathering of data by "virtual means" is suggested as a solution as opposed to all-encompassing records to deal with the ownership problem in point 2 (Vikkelsø, 2010). Bergmann et al. (2006) describes the notion of virtual means as a multi-tiered distribution as opposed to a large centralized storage, somewhat similar to HISP where distributed repos' aggregate data upwards as necessary (Braa et al., 2007). The gist of these ideas can be described as a negating a problem of complexity through making adaptable systems that gather bits and pieces of data from various sources. The idea is applicable in the case of MHB, if one appropriates the phrasing "by virtual means" as actions that can be carried out by a user and not necessarily by a system.

Securing private data is the final point on the list. Common to all of these solutions are the shared problems of asymmetrical cryptography, key management and strong organizational routines for security (Bongartz and Unger, 2011). Strict security regimes should naturally be deployed in all matters involving sensitive data, such as health data, but the problem is not exclusive to the realm of health information systems. In layman terms, the challenge is how one can allow a secret (the patient data) that should be known only by the user to be manipulated somehow by someone or something else, without that someone else gaining insight into the secret. The short answer to this problem is that there is no solution that allows for knowing and not knowing a secret at the same time, for fairly apparent reasons.

The best option is to create a technical implementation that does not require the ability to open or read the contents of the patients' files. This option only allows for transferring the encrypted files to the user, and not letting MHB manipulate them in any way. This also means that the user would need a means of decrypting the files once they have received.

This introduces several problems, such as being dependant on client side tools for decrypting, such as java (not always available) and JavaScript (not optimized for decrypting large amounts of data, e.g. images).

The other option is to allow MHB to decrypt the files before sending them over a secure connection to the user, but in order to do so, MHB would have to store the passphrase that must be used to unlock the files. This passphrase can of course be encrypted by a master key, but the fact remains that at least one system administrator would have the technical ability to unlock all the files. The only remedy against this situation is to create strong organizational mechanisms and auditing that prevent this kind of activity. In sum, the trade-off is between flexibility (low security, trust based) and cumbersome management with multi-factor authentication (high security, key generators).

3.1.2 Practical lessons of patient empowerment

The account of the problems that arise in health information infrastructures, along side the account of IIs in general, outline an understanding of how one should interact with IIs. II theories affect the choices that can be made with regards to the execution of MHB's implementation and integration. Another, and different question of interest is what other projects that aim to achieve a degree of patient empowerment have learned about the role of their systems, and how it affects patients. In other words, MHBs class of systems should provide value for the target audience, which typically arrives in the form of control and power.

Vikkelsø (2010) quotes Winthereik (2008) who has shown how the envisioned responsible patient, as a result of various empowerment initiatives, isn't quite in line with what was expected in terms of what the idea of empowerment was intended to mean. In an empowerment study with patient access to maternity records the test participants focused more on information gaps and errors more than anything else, instead of becoming better patients. Arguably, a large focus on what is essentially an editorial role is not a kind of patient empowerment that holds great medical value. Winthereik (2008) argues that a better patient is one who is better prepared for consultations, facilitating for better communication

between patient and doctor.

Assuming an editorial role is certainly not void of meaning, as the complex nature of health care work often creates data errors, which can be nearly invisible or silent (Ash et al., 2004, p. 105), typically resulting from poorly designed patient care information systems. The busy life of the health care worker can easily produce errors that have real and dangerous impacts on a patient care trajectory. An estimate of 850,000 incidents and errors occur in the US each year, and medication errors alone have been estimated to cause 80,000 hospital admissions in Australia (Ash et al., 2004, p.104). These numbers legitimize patient scrutiny of journals.

However, the goal of a patient centred or patient controlled system should not be this alone. As usage of similar systems trend towards editorial actions, legitimized as they may be, their focus can over shadow other desired applications of the system. Cummings and Turner (2010) found that there are highly varied sets of reactions to the introduction of web based information, resulting from factors such as the severity of the disease, self-image, family context, confidence, social support and disease understanding, and that understanding the value derived from patient information systems is not clear cut. Understanding what brings value in the case of patient centred information systems is absolutely paramount when designing solutions.

Failure to understand users and their context of use has long been recognized as one of the biggest points of failure in IT development (Kushniruk and Turner, 2012, p. 353). In order to make safe e-Health systems Kushniruk and Turner (2012) argues that users have extremely varied profiles, and that their inclusion in the design of e-Health systems is a must in order to map the risks of unintended consequences. This statement has a normative effect on the methods of design, basically making an argument for user involvement, which the action design research methodology applied in MHB does extensively.

Besides from method considerations, Kushniruk and Turner (2012) also shows that because patients represent such great variety, one cannot identify general principles of patient empowerment design without knowing who the target audience is. Factors such as age, sex, computer

literacy and roles of health care workers in various fields come in to play. A design consideration that must be taken is therefore not only how to provide immediate value for a small user group through bootstrapping the design process, but also for whom.

Chapter 4

Design Methodology and Methods

In this chapter I will account for the research design of this thesis, which has two parts. These are the methodology and the methods that make out the pragmatics of executing the research design. It is not uncommon to not make a clear distinction between methodology and method. I take care in making a distinction in this thesis, because the chosen methodology is not very commonly used, and thus in order to avoid confusion I distinguish between "traditional research methods" (observation, note taking, audio recording, etc.) and the methods that are inherent in the action design research methodology.

The methodology that the work behind this thesis adheres to is that of *action design research*. As is with any methodology within the science fields, they are interpreted with various degrees of nuance with respects to the different contributors. In this thesis, the understanding and usage of action design research (ADR) is based of the contributions of Hevner et al. (2004), Hevner (2007), Iivari (2007a), Iivari (2007b),Sein et al. (2011) and Checkland and Holwell (1998). The main contribution is from Sein et al. (2011). ADR owes its legacy to the methodological paradigm called design science, with which it shares great many similarities. Because of the shared legacy with design science and its longer and publication history, i will first account (briefly) for the history of design science, then its philosophical grounding, and finally extend it with action design research.

4.0.3 Design science history

Design science argues for the study of the artificial in addition to the study of the natural. Simon (1988) popularized the view that there is value to be had from studying the man made, even through making as a method. He contrasted how the view of conducting research and practice had been dichotomized:

> Historically and traditionally, it has been the task of the science disciplines to teach about natural things: how they are and how they work. It has been the task of engineering schools to teach about artificial things: how to make artefacts that have desired properties and how to design.

Simon made no effort to hide that he believed that the cause of the trend towards the pure science was for reasons pertaining to "hankering after academic status". He described this as a problem that was rooted in the un-teachability of the practical. Professional schools *did not know how to educate for professional design at an intellectual level appropriate to a university; the newer kind of school has nearly abdicated responsibility for training in the core professional skill. Thus we are faced with a problem of devising a professional school that can attain two objectives simultaneously: education in both artificial and natural science at a high intellectual level* (Simon, 1988, p. 68). The problem that Simon recognized was that the act of designing and executing a design was not void of academic value, but that the knowledge one could derive from design science was not easily distilled. What exactly would be the output of a design science study?

What one could learn from a design process was not descriptive, rather, it was normative, and it concerned itself with the "should" of design. However, the formulation of design imperatives are only simple in the most trivial of cases, particularly those that could be reduced to quantitative measures, for instance diet plans. Simon (1988) gave one such example, outlining that the "should" of a diet plan was to declare an interior and exterior world, e.g. what kinds and quantities of nutritionals the body needed over the course of one day (interior parameters) and the exterior world that would restrict the possible solutions, for instance the cost

and availability of certain foods. In short, the problem of formulating imperatives, or "shoulds", was to find the optimal solution given a set of restrictions in the possible worlds (or domains) in which a problem could exist. Of course, this becomes more difficult when the problems one aim to design solutions for are of a less trivial and quantitative nature.

As design science evolved over the following decades, it started to develop various branches and perceptions on how the problem of arriving at normative statements about non-trivial issues evolved. Gregor and Hevner (2010) discusses the various natures of research contributions in the different applied understandings of design science. Gregor and Hevner (2010) places the types of contributions along an axis of less / more abstract, where the most abstract represents theories, and the least abstract represents instantiations (products and processes). In the middle we find constructs, methods, models and partial theory under the contribution type label of design principles.

The study demonstrates that there is a wide range of applicable uses for design science, but also that any given design science study can yield contributions not on just one, but several levels. It clarifies however, that for the non-trivial, complex socio-technical cases one must take great care to arrive at an understand of the problem domain, particularly how the artefacts under study can affect and better a situation, through design, that is constrained by its exterior.

4.1 Design Science

Design science is a methodology for conducting research where the method of inquiry is the design of the novel. The first and most obvious question that comes to mind when one claims that research can be done by creating something is what and how one can acquire knowledge from the process. The question is legitimate, because as everybody knows, new artefacts and novel ideas are put to life all the time, but that doesn't mean that they contribute to the sum of human knowledge. In order to learn from creating one has to adhere to a methodology of conducting design that provides expressive knowledge on the subject matter, such as design science.

Hevner et al. (2004) presents a framework for conducting design science that is divided into three cycles. The three cycles that are proposed are "the relevance cycle", "the rigor cycle", and "the design cycle". Figure 4.1 shows the activities and cycles in a design science study. The left-most column describes the environment in which a particular problem should be solved. The right-most column shows the knowledge base, how it is applied, and how it will be expanded with additions to the knowledge base as an output of the IS Research. The centre column contains two activities, which are develop/build and justify/evaluate. These activities are set up as iterations, so that one informs the other by cycling through them.

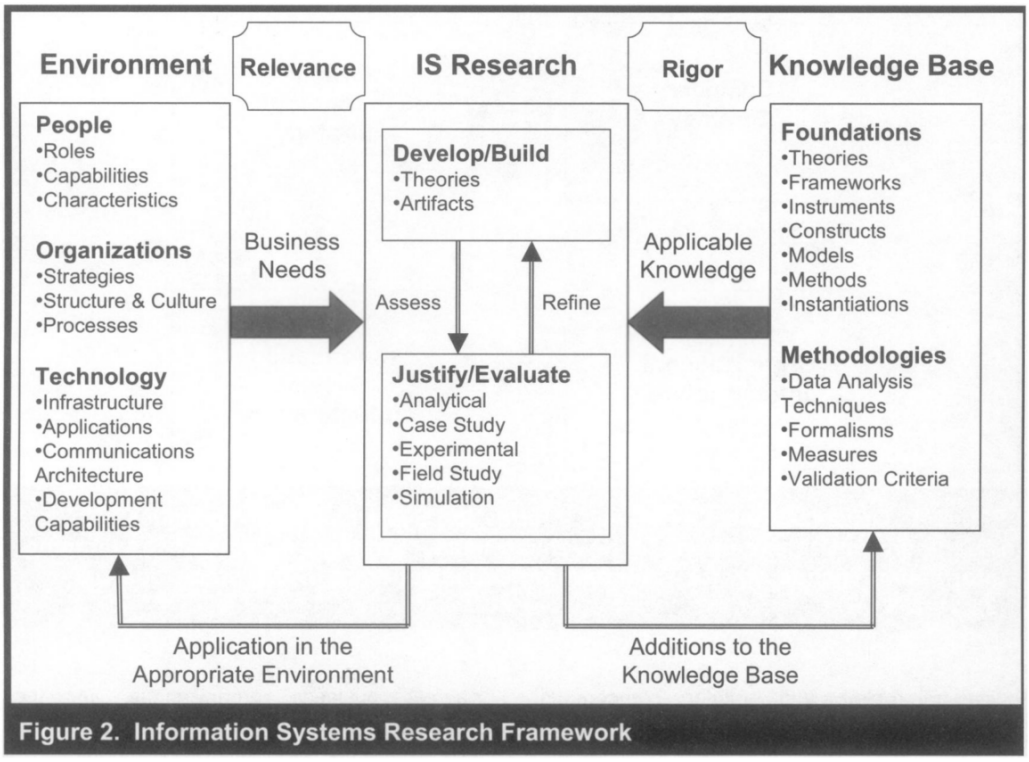

Figure 4.1: Design science research framework from Hevner et al. (2004, p. 80).

4.1.1 The relevance cycle

The relevance cycle bridges the contextual environment of the research project with the design science activities (Hevner, 2007, p. 88).

A design science activity is not void of environmental context. A design

science activity relates to a context as it seeks to *improve the environment by the introduction of new and innovative artefacts and the processes for building these artefacts* (Hevner, 2007, p. 88). The environment in this context consists of *the people, organizational systems, and technical systems that interact to work toward a goal. Good design science research often begins by identifying and representing opportunities and problems in an actual application environment* (Hevner, 2007, p. 89).

It is the context of MHB that serves as the input requirements for the design research project, and also the success evaluation criteria. This relationship defines a cycle, as the only way to define whether an implementation has been successful or not is to return it back into the environment, where descriptive methods for evaluation may be applied. The feedback from the environment decides whether additional iterations of design are required. The feedback might also uncover that the initial requirements were incorrect (Hevner, 2007). Design science is critiqued for viewing *organizational intervention as secondary* (Sein et al., 2011, p. 39).

4.1.2 The rigor cycle

The rigor cycle proves past knowledge to the research project to ensure its innovation. It is contingent on the researchers to thoroughly research and reference the knowledge base in order to guarantee that the designs produced are research contributions and not routine designs based upon the application of well known processes (Hevner, 2007, p. 90).

There are two key aspects to the rigor cycle. The first is that one has to ensure that what one is creating is in fact a novel artefact, and not just the application of well-established knowledge to a routine problem. This is achieved by thoroughly delving into the knowledge base that describes past phenomena in order to identify what distinguishes your research and design activity with that of others in the past.

The other key aspect is that whilst the rigor cycle is dependent on the investigation of past phenomena to identify its novel aspects, it is not dependent on the application of kernel theories for the design and creation of the novel one seeks to make. In accordance with Iivari (2007a), Hevner (2007) agrees that *it is often a stretch to find kernel theories for the*

creative activities of design research [...] to insist that all design research must be grounded on descriptive theories is unrealistic and even harmful to the field. (Hevner, 2007, p. 90). Some designs redefine the rules, and their exploration should be encouraged without forcing designers to rely on grounding to theory.

Simon (1988) explained the relationship between the creative process and the application of kernel theory quite well. The creative act of designing should not be guided by grounding in theory, but it should be limited by the available options in a problem domain. In other words, kernel theory is used as a minimum to define the "game rules" under which one can be creative, as defined by how one perceives and understand the environment of towards which the design should have relevance. In other words, kernel theory is applied to define the environmental constraints, but not necessarily the design activity itself.

The output of the rigor cycle is *additions to the knowledge base [...] that will include any extensions to the original theories and methods [...], the new meta-artefacts (design product and processes), and all experiences gained from performing the research and field testing the artefact in the application environment* (Hevner, 2007, p. 90). What the rigor cycle puts back into the knowledge base, i.e. its output, are design principles that address classes of problems. This means that the formulation of the output must be in the format of classes of solutions.

4.1.3 The design cycle

The requirements are input from the relevance cycle and the design and evaluation theories and methods are drawn from the rigor cycle. However, the design cycle is where the hard work of design research is done. (Hevner, 2007, p. 90).

Being described as the heart of the design science practice, the design cycle commentaries from Hevner are fairly short. The reason for this has to do with the contextual nature of design. The act of designing entails a variety of activities, but at its core, and common to all fields, are the actions related to architecting, designing and building artefacts and processes. Depending on the field under which the design is carried out, the applied methods can be many. However, in accordance with the three-cycle view,

the important notions in the design cycle relate to the shifting between building and evaluating, and the designs grounding in the knowledge base (rigor cycle), and contextual relevance towards the environment (relevance cycle).

4.2 Extending the Design Science methodology with Action Design Research

Both DS and ADR aim to develop a class of solutions for a class of problems. The difference in the ADR extension more or less lies in whether or not organizational intervention should be in focus. This view inherits from the socio-technical nature of action research, which views artefacts as deeply bound with social life.

For the purpose of also accounting for social change the concept of an ensemble is introduced in ADR. An ensemble is defined as *the material and organizational features that are socially recognized as bundles of hardware and/or software* (Sein et al., 2011, p.38). In the case of MHB the ensemble under investigation is the patient and her patient health data. Here patient health data is understood as a socially recognized feature of the health organizations that issue them, that manifests in various forms (electronic records, paper printouts, etc.).

Both Iivari and Orlikowski view the ensemble artefact as emergent from an organizational context (Sein et al., 2011). The ensemble artefact is *ingrained* with theory. Theory in this context means *the power to generalize* (Sein et al., 2011, p. 40). For MHB this implies that one part of the ensemble, the patient health record, is ingrained with organizational theory that allows for generalization. The scope of generalization available for any ensemble artefact is of no fixed size and must be defined by the one who wishes to generalize. In our case the aim is not to derive a general theory from the artefact, but rather an ensemble specific-theory. This is echoed in the problem formulation of this thesis.

Action design research is conducted in stages in, where stage 2 is iterative. The stages are 1) problem formulation, 2) building, intervention and evaluation, 3) reflection and learning and 4) formalization of learning.

Within each of these stages there are several new concepts that I will now briefly account for, along side a more detailed account of what each stage entails.

4.2.1 Problem formulation

Problem formulation is the first stage. This formulation requires input from somewhere in order to gauge the initial path to follow. Input can typically come from potential users, domain experts, technological aspects of the ensemble under investigation and theory that explains the relevant field (Sein et al., 2011).

In MHB the problem formulation stage produced the research question of this thesis, alongside several guidelines that would influence the design of the following build phases.

4.2.2 Building, intervention and evaluation

Each cycle in the ADR methodology produces a new variant of the designed artefact (building). This artefact is then introduced into a context (intervention), and evaluated by the design team based on the feedback of the users who were exposed to it, balanced against the theory input to the project.

These cycles *interweaves the building of the IT artefact, intervention in the organization, and evaluation* (Sein et al., 2011, p. 42), BIE for short. These BIEs can either be IT-dominant or organizational-dominant. The direction of the domination is largely influenced by whether a new artefact has been envisioned from the start or not. In the case of MHB, the BIEs are IT-dominant, and the theoretical backdrop for design is information infrastructure theory and patient empowerment theory.

MHB conducted two BIEs named alpha and beta, in addition to one pre-alpha stage which is the execution of stage 1) problem formulation. After a BIE is carried out the next step is to analyse the need for a new BIE cycle, and if found necessary, to adapt the form of this cycle in order to create a new variety of the designed artefact.

4.2.3 Reflection and learning and formalization of learning

Reflection and formalization of learning conclude a BIE. The outcome of each BIE is analysed in order to identify if any classes of problems were addressed, and if the process and artefact divulges any classes of solution to the problems. These solutions come in the form of guidelines that can be employed by others.

4.3 Design and evaluation methods

So far in this chapter I have presented both design science and action design research, identified their shared philosophical base, similarities and dissimilarities, and accounted for how the methodology has been employed in the MHB project in the form of the projects research design. In the following section I will describe the methods used within the methodology. Two classes of methods are introduced in this section. One is the method used to conduct the evaluation, the other is the method used to conduct the prototyping activity. The prototyping activity is denoted as the central shape labelled "prototyping" in figure 1.1. This activity is conducted in iterations that will be presented later in this section.

Regarding the other methods, Hevner et al. (2004) presents seven guidelines for design science research, where guideline number three states that the utility, quality and efficacy of the design artefact must be rigorously demonstrated via well-executed evaluation methods. The selection of evaluation methods need to be in harmony with the problem formulation and suitable for discovering both classes of problems and solutions. Because of the emergent nature of the research design each cycle needs to decide on which methods to employ in the next evaluation cycle.

For MHB the first cycle used a workshop as its method of conducting an evaluation with test participants. For the second cycle the method used for conducting an evaluation was audio taped and transcribed one on one interviews where test participants interacted with the artefact.

Workshop as a method was selected because of the state of the artefact in the first prototyping iteration. At the time of the workshop the prototype was only a shell-prototype that simulated certain interaction flows. Because

of the limited interaction the prototype offered, it would have been of limited value to evaluate in a one on one interview. The limited possibility of interaction made suitable a scenario where the artefact was presented and discussed by many people at the same time.

The purpose of the interview method for evaluation was to uncover as many potential influences as possible, which can be achieved by longer interviews. Interviews were carried out in the second iteration, where the state of the prototype allowed for much deeper and complex interaction. The increased detail level that could be recorded from test participant interaction warranted one on one interviews. Statistical validity has never been a goal, rather the evaluation has been about identifying and accounting for potential black swans (Flyvbjerg, 2006). In short, are there any major logical flaws, or perhaps generative capacities, in the implementation of our idea that we were unable to foresee ourselves?

Test participants were recruited for the workshop either through personal contacts of the entrepreneur doctor, or through the home page of the Norwegian diabetes association. For the evaluation in the second iteration we had hoped to amass a sizeable user base in the prototype, which now had reached the open beta phase. We had prepared a questionnaire that we would send to the amassed users, inviting them to answer some questions or to be interview, but unfortunately the beta never gained any traction and we had to find other willing test participants. Test participants were instead recruited by myself from colleagues and friends.

In addition to feedback and evaluation from test participants the core activity that produced knowledge was the act of designing the artefact. The continuous process of negotiating theory, user feedback, expert user evaluations and design problems divulged many interesting problems, and proposed many novel solutions.

4.3.1 BIE cycle design in My Health Book

An example of an IT-dominant BIE cycle design is provided by Sein et al. (2011) in the form of a diagram (see figure 10 in Sein et al. (2011)), exemplifying several iterations, their outcome, feedback and contributions.

This diagram has been adopted in the following form for the MHB project:

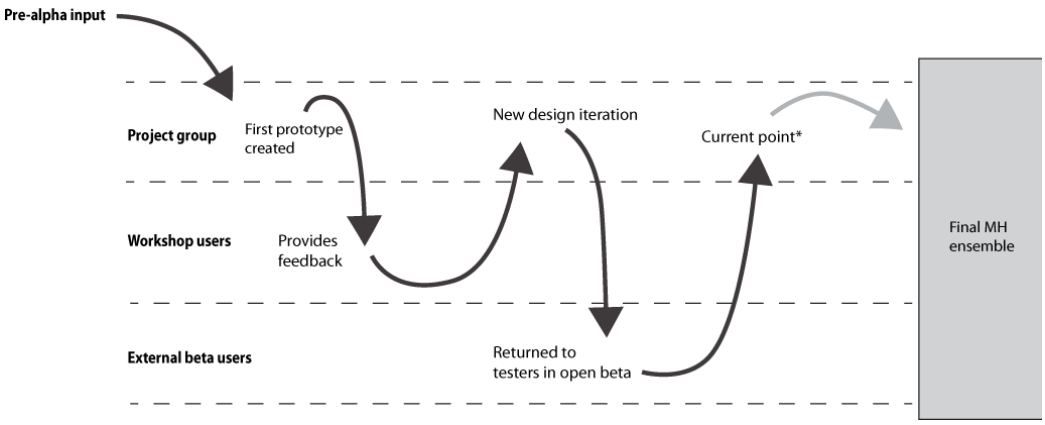

Figure 4.2: My Health Book BIE design, adaptation of figure 10 in Sein et al. (2011)

In the top left hand corner we find the pre-alpha input, or problematization stage. This stage is left out of the cyclic representation as it did not entail a build phase. BIE design iterations move vertically between feedback instances in figure 4.2. The first prototype, nicknamed the shell prototype, was built on the basis of expert knowledge and a set of design guidelines as a result of the pre-alpha stage. The alpha prototype was presented to the workshop users that provided feedback on all dimensions of the prototype, i.e. role, implementation and look & feel.

Feedback on the concept and design was provided and returned to the project group that started the second design iteration. New specifications were developed and the prototype changed before it was returned for evaluation in the beta.

Design specifications for the final MHB ensemble was based on feedback and evaluation from the alpha and beta phases. The progress of the project as of this writing is marked in figure 4.2 as "current point", and denotes that the artefact has not yet reached its final form. A final MHB ensemble can possibly be the product of a third BIE iteration, depending on the findings and implementation possibilities outlined in the analysis of this paper.

4.3.2 Methods and feedback data in BIE 1 - Workshop and discussion

A workshop was carried out for the first BIE. The participating individuals were recruited via the entrepreneur doctors' connections. All of the participants either had or were affiliated with someone in a long-term patient role, or had a professional role connected to medicine. The workshop participants (aged about 35-60) characterized themselves as follows:

- P1: Employed in a health authority organization, educated as a veterinarian.
- P2: A nurse, new patient.
- P3: Frequent patient, frequent user of the health system. Previously employed in a medtech company, retired.
- P4: Patient, bioengineer.
- P5: Mother of child with diabetes.

Members of the project group were active participants in the discussion. I had the role of secretary, writing a transcript, and only intervening in the discourse to clarify on unclear statements. I was also responsible for demonstrating the shell prototype. During my presentation my supervisor took notes of the comments from the attendees. One group member whose role was to provide input on legal and ethical questions took active part in the discourse. His presence was noticeable, on par with the other attendees. A total number of 9 people (including researchers) were present and seated in a horseshoe formation.

First my supervisor welcomed the participants, and then the entrepreneur doctor introduced the concept by talking and displaying slides that he had prepared. He did not introduce any screen layouts, nor did he engage in demonstrating functionality. He mainly talked about the concept, which prompted dialogue and feedback from the room over the course of his presentation.

After a short break where some light food was served, my supervisor held a thematic discussion with the participants. This discussion was intended to prime the participants on the subjects that the shell prototype implemented in one way or another. Themes that were discussed were who they wanted to share information with, what type of information they wanted to share, and in which situations they wanted to share. Other themes that were discussed were what kind of information was too sensitive to share, security and if they perceived if a service such as MHB was something they would be willing to pay for.

After my supervisors thematic discussion I introduced the shell prototype and exemplified the intended usage and flow. Participants were eager to interact, and gave feedback and asked questions as I presented. My supervisor took notes during my presentation. After my presentation there was feedback and dialogue, where additional issues and questions were raised.

Audio recordings could not be carried out because of the distance between the participants and large number, making it difficult to separate participant input during playback. In stead transcripts were written on the fly by two members of the project group. The detail level in the transcripts was close to verbatim.

The data that was gathered in BIE 1 was broad and covered many areas, but mainly it covered the role and the implementation of the concept. Less focus was given to the look & feel dimension.

After the workshop the transcripts were distilled into thematic data and analysed with regards to response given to the concept (role) and implementation (functions for gathering, organizing and using data). Aligned in a matrix the data was interpreted to identify trends and important points for further exploration.

Feedback data was used to revise the requirements for the artefact by the project team, both adopting and rejecting new ideas, taking care to negotiate the newfound knowledge with the applied theory and understanding of the environment and its technical limitations. A new build phase was initiated which produced a new version of the artefact that was tested in BIE 2.

4.3.3 Methods and feedback data in BIE 2 - Focused interviews and user testing

For the second BIE a total of 5 (including one general practitioner) qualitative interviews with a selection of new test users were performed. The interviews were carried out individually in a semi-structured fashion with recruited users and followed an interview guide (see appendix). P6 to P9 were in their mid 20's, P10 was in the early 50's. The interview participants characterized themselves as follows:

- P6: Student of informatics, also works as a web developer
- P7: Works as a motion graphics artist
- P8: Student in product engineering
- P9: Student of informatics
- P10: Doctor, GP.

In BIE 2 audio recordings were created for each of the individual participants . Participants were informed of this prior to the interview and all gave their consent. Verbatim transcripts were produced after each interview and the answers given were input into a matrix with 5 columns with the participants, and the corresponding interview guide questions in the following rows. About 80 per cent of the replies to each question were concordant in equal to or less than 4 of the interview participants.

Only P7 in BIE 2 had previous experience with the MHB prototype on his own. He had spent two weeks using the system without guidance. A brief introduction was given to the rest of the participants in BIE 2 prior to the interviews, but largely they had to explore the systems themselves prior to and during the interview as I posed questions and asked them to perform tasks. As they performed tasks they commented on the interaction and concept. The prototype became a tool for invoking reflections about the role of the system, and not only the implementation and look & feel.

Because of the high resolution of the prototype (Houde and Hill, 1997), all the test participants received explanations on what the prototype was and how they could expect it to function, to lower their expectations, and

remove any confusion about the difference between a prototype and a finished product.

The attached interview guide (see appendix 1 - Interview guide) was originally designed for users who had used the system on their own for some time, but we were unable to recruit test users in time. Only the first portion of the interview guide was used, seeing that the second portion related to experiences over time.

The interviews were carried out in different settings. Two of them were performed at the university, using the interview objects own computers to access the web site. An iPhone was prepared with the prototype app and given to the participants so that they could try it and carry out tasks.

Using the web site and the provided iPhones the participants took pictures of various standard medical forms and uploaded them. The documents that were provided contained actual medical data, where information that could identify either patient or physician had been redacted. The nature of the represented incident was a broken forearm. It was important to use actual medical data to create a realistic setting, and it was also important to use an example incident of low sensitivity, as opposed to an example that could be prone to taboo (see appendix 2 - Example medical document).

Chapter 5

The My Health Book Prototype Design and Evolution

This chapter is structured in a chronological fashion. To start with I will present the overall concept and design principles that were produced in the pre-alpha stage. Based on this I will present the alpha and beta evolutions of the prototype.

5.1 Pre-alpha - background and initial evolution of the project rationale

The desire for the project, on the part of the entrepreneur doctor originated from the situation in the health care ICT infrastructure in Norway. The doctor expressed that doctors and surgeons in the health care institutions spend a large amount of time attempting to aggregate patient information from various sources. Often this work consists of looking through records, which might or might not be connected with other systems that hold relevant information on the patient, as well as making phone calls and talking with the patients themselves. He recognized that the problem of getting data was because of the vast and complex landscape of health IT. What he believed was that there really isn't any reason why the patient herself can't manage her health data, and by doing so bypassing the complexities of the infrastructure, at the same time as alleviating him of the burden of gathering data. Also, the fragmentation in health care ICT

is obviously a nuisance for health care professionals, but more importantly it is also a danger to the patients health. When health personnel have to rely on fragmented and unverified sources (patients forget) for their diagnostic tasks, then they run the very real risk of making the wrong decision. In addition, many of the systems the health workers have to rely on are simply poorly built. For instance, many systems impose an un-natural sequencing of tasks in an assumed interruption free environment that cause perpetuating journal errors, errors that undeservingly are credited to the physician who had to operate the poorly designed system (Karsh et al., 2010). If patients to a greater extent were to bring with them their records, then they could at the same time review and point out these errors.

As My Health Book was envisioned by the entrepreneur doctor, it was to be a system that is patient controlled, running on a website or an app, and the data elements that was intended to fill the system was the paper record. Health data is created by medical personnel, and the patient is entitled to request a copy of records in her journal. In essence, My Health Book will be a content management system for patients with the option of sharing your content with a medical professional.

The design vision has two distinguishing features. First of all it is a private initiative, and so the patient data will have to trust and relate to a private organization. This organization does not claim ownership of the data that the user uploads. Second it is based on paper journals that the patient herself requests from her healthcare providers. Using paper as a medium for transfer undoubtedly has an air of "old fashioned" to it, but it is also interesting because it builds upon the principle of installed base cultivation and gateway strategies (Hanseth, 2001).

Paper gateways have been explored elsewhere (Braa et al., 2007), so has the idea of patient-centred care (Berwick, 2009) and patient empowerment (Ueckert et al., 2003) to name just a few. My Health Book, as proposed by the entrepreneur doctor, would encompass all of these elements. What made the project analytically interesting was the socio-technical context it was proposed in and how it's proposed ways of doing this were in contrast to many of the other initiatives.

For instance, other initiatives for patient control over health data were

usually an initiative of a hospital, such as MinJournal (My Health Record) (Grisot et al., 2013) or akteonline.de (Ueckert et al., 2003) and they were very specialized within a certain field of medicine. In addition, data was either served directly from the service provider into the system, or it was input by the patient into web forms with fields that were custom designed for different medical states.

Philosophically, My Health Book is similar to many other patient centred IS, but the methods proposed by MHB for gathering, organizing and using data are dissimilar in the sense that they only aim to deal with one data format, that is the paper and its digital representation. Paper is a highly immutable artefact that can exist in a system with minimal complexity. This opened up for My Health Book as a service that supports any kind of health data as long as it can be represented on a piece of paper.

If such a system could function and prosper is a key question. Would potential users of My Health Book (MHB) be satisfied with a very limited set of functionality and the use of paper? And would the patient plus patient record ensemble survive a contextual shift from health organizations (in one data format) to a private solution (with a different data format) and still support the notion of patient empowerment, and at the same time provide added value for the patient-doctor relationship?

5.1.1 Outcome of the problematization stage

It became clear that the project posed interesting challenges worthy of further investigation after the project team had spent a fair amount of time discussing what they believed MHB should be. We were particularly taken by four aspects (patient control, limited freedom, disconnected from health II and paper based). I would now like to elaborate on what these aspects evolved into during the discussion of the project preamble, the problems they posed, and how they became guides for our design.

Patient controlled

Nobody but the user herself would put data into MHB. It is not automatically extracted from anywhere. This implies that the patient can

chose what data to store and what to omit. Users can also opt to share the contents of MHB, and hide certain documents from sharing. They can also organize the documents and data as they like, within a selection of 5 pre-set categories. This function set and its implementation defines how MHB technically determines what the limits to term patient controlled are. As offered, they are within the definition of patient-centeredness as it is put forth by Berwick (2009, p. w560): *The experience (to the extent the informed, individual patient desires it) of transparency, individualization, recognition, respect, dignity, and choice in all matters, without exception, related to one's person, circumstances, and relationships in health care.*

Berwick (2009) describes himself as an extremist on the axis of the possible definitions of patient centeredness, but what is interesting to note here is the part of his definition he has in parentheses: *to the extent the informed, individual patient desires it.* His definition of centeredness is close to what I in this thesis have called control in the sense that the more conservative definitions of patient-centeredness usually involves a maxim of the patient always being involved. Control includes the option of not having insight into ones papers. It also includes having insight and not wanting to share it.

MHB will therefore be patient controlled in the sense that you can choose to use it (not mandatory), and that if you do choose to use it you can do what you will with the data; You can upload what you want and select where to store it, name it as you please, keep it for just yourself, reference before or under a consultation, or even remotely share it, something which previously has been limited by the closed network that health providers have to be connected to.

It is your data, you can do with it as you please. By law the institutional health providers have to be very careful with how they handle your information, but once it has been given to you by legal and established means, it is completely up to the individuals own discretion what you do with it. If someone deems MHB to be a safe and handy place and method of storing it, then there are no laws that prevent one from doing so. The juridical zone that MHB operates in can be described as "a yet unexplored legal opening". It is completely up to the discretion of the patient to decide

how, where and why their health data should be stored or used.

One problem that emerges in this is the patient ability to withhold important information, knowing so, or simply by not knowing what is important to share with medical personnel. This problem was discussed, and the project group arrived at an understanding of this problem as one that already exists. In the current situation doctors still have to question patients.

Limited freedom (Simplicity / flexibility trade-off)

Health care data is produced in a complex system, for complex and varied health issues, and in order to sufficiently represent the patient, her issues, and the organization that deals with her as a patient, then the data itself must also be complex. The information systems that support this type of data, besides from legacy systems, are typically created in an object-oriented fashion. Object orientated programming produces relational-models that aim to mirror the essential components of an organizational system, in essence producing databases and programming logic of equal or greater complexity to the formal operations of the business (Hasle, 2008). This complexity is not, as many will have it, redundant. This assumption clearly needs some backing arguments, which will mainly revolve around the idea of complexity.

As Norman (2010) aptly put it, complexity is not the opposite of simplicity. In his book Living With Complexity, Norman made a very good point about how people usually confuse the relationship between complexity and simplicity with the concept of the "simplicity / complexity trade-off", or in other settings (typically related to design) as the "usability / flexibility trade-off". The idea is fairly straightforward, and can be described by the use of the TV remote control as an analogy;

The remote control can be very simple, e.g., it can have a button for on/off, volume up /down and channel up/down. All in all, these are the most basic functionalities you need in order to watch TV. This kind of remote control is very easy to learn how to use, but not very flexible. On the opposite side of the scale we have the remote controls that we are most used to today. They look like something out of Star Trek, with a plethora

of buttons, many of which have never been pressed. Very flexible, but not very easy to use, or as some might say, very *complex*. In the TV remote control example it is clear that simpler is not necessarily less complex. The goal of the designer should be to manage complexity, not to over-simplify it (Norman, 2010). This represents a challenge for MHB, as the problem it will address is complex, and it will attempt to do so with very simple functionality.

Simplicity in a "Steve Jobs kind of way" was the mantra that the entrepreneur doctor proposed: 5 Pre-defined categories for organization, and only allowing for uploads of images. The system had to be so simple that "grandma Olga" could use it. The question of simplicity then started to revolve around how simple can we actually make something like this without missing out on "good" complexity, the kind of complexity you need to ever have a chance of making sense of the system? System complexity has to match the mental model of user expectance with regards to what the system can actual do. As demonstrated, less complexity is not always simpler. In the case of MHB the organization of documents under pre-set categories and limits with regards to input types (images only) can be described as simple in the sense that it is not very flexible.

It was decided that MHB should try to keep things simple, and through user feedback we would identify what was missing and further discuss how to implement it. This way we would essentially adhere to a bottom-up, bootstrapped (Skorve and Aanestad, 2010) process, more or less the opposite of the de facto process strategy employed by the governmental actors that dealt with the same problems and solutions. We realized that this was a tight-rope walk between simplicity and flexibility in order to arrive at a usable solution, however, we believed it to be better to create a solution that was too simple rather than too complicated, so that the core features could receive full attention in order to provide immediate value. Missing features could be added later.

Information Infrastructure disconnect

The prototype was to be built with no direct technical (as in digital) connectivity towards any other existing information infrastructures. This

was one of the key aspects of the concept, namely that we aimed to employ the paper and camera/scanner as a gateway (Hanseth, 2001) towards other health information infrastructures. The ensemble of paper and camera is understood as a gateway in respect of its alternatives. These alternatives could for instance be a setup where MHB relied on detailed data entry into standardized forms, or transferring data using XML. In either case the standards of the health information infrastructure would have an effect when imposed upon MHB as an information system. By using paper as the data carrier and exploiting its peculiar properties we can at least attempt to bypass the problem of maintaining and deploying standards by reducing our dependency on complexity, in essence building on the installed base (Hanseth, 2001).

Brainstorming sessions gave rise to several other means of interfacing with the health II, but they were quickly dismissed as all the ideas that were produced involved the inclusion of other actors, several complex technologies, and having to adhere to the organizational and bureaucratic structures that partnering would entail. The promise of these kind of problems were too close to what we perceived to be the problem in the health IIs, the very cause of MHB as a project, so volunteering into these structures would be counter-productive. However, information infrastructures are socio-technical. Is it possible to bypass complexity and side-effects (Hanseth et al., 2006) through social channels? The exercise of designing and building a digitally disconnected IS would shed light on these questions.

Paper as data

Paper as a data format is imbued with several properties that make for an interesting subject of analysis. It is of low technical complexity, its shape is (usually) a pre-set standard, but the formatting imprinted on it can be anything and everything. As a carrier of information, paper imposes no other structural limitations than the available space on the page. It is also analogue, which makes it a less than obvious candidate for input to a system which aims to sort and utilize the data the paper contains by digital methods. The way via paper is cumbersome, but with the cost of having

to import the papers contents into a digital system we find reward in the fact that this method does not impose any new technical or organizational re-structuring of the existing health information infrastructure installed base.

Using paper as a strategy was the result of the limits imposed upon the project by the information infrastructures nature. The IIs offered no other apparent information gateway that did not require a tight coupling with existing systems in the public health II, one of the reason for the perceived need of a project such as MHB. Complexity is difficult to navigate, and paper offers itself as a way into the health IIs. But paper is obviously not problem free. For instance, how will the users be able to manipulate a camera, or scanning equipment, so as to take decent pictures, and is the camera quality good enough for various types of medical documents?

5.2 BIE 1 - First prototype and workshop evaluation

After the project group had settled on the overall design concepts, a shell prototype was created for the first workshop. This prototype simulated the interaction that was carried out by a typical user on an iPhone. A shell prototype was not produced for the web site. The web was developed in the second cycle, and will be presented in next chapter.

Figure 5.1: My Health Book alpha app screenshots

Figure 5.1 is a montage of 9 of the key interfaces that depict a user story. Line by line they depict the login and registration process, the

category interface, displaying of documents in a category, the "waiting for picture" upload screen (accessed from the main menu, lower left corner), the following display that asks for a filename and category, and a screen depicting upload progress. The last two images on the bottom right depict the envisioned sharing process, based on the name of the person you are sharing with, their HPR-number and a predetermined selection of 1 hour, 24 hours or 1 year sharing time.

The login screen has a "remember password" toggle. As many on the project team were avid users of apps that connected to online services and had experience with the cumbersomeness of typing in your password every time you use an app, we believed that it would be beneficial with such a toggle.

In the registration form there is a feature for registering an account on the behalf of someone else, in addition to registering an account for yourself. The difference between the two is that the in the screen where you can register on behalf of someone else you can select if you are some ones parent or legal guardian. For this feature you would have to enter information on both parties, and the birth date of the represented party. The intended usage for this was for parents creating accounts for their children, and that once the child reached proper age and legal capacity the account would be automatically transferred to their control.

Creating and uploading documents followed a model of first taking an image with the app, and then selecting its name and category. This sequence of events was designed to mimic the typical flow of "author a document and then save it", much like you would on a personal computer. This design was chosen for its familiarity.

Sharing the contents of your health book required both the name and HPR of the person you wanted to share with. Since sharing had implications for both the sharer and share recipient, it was decided that sharing should be time restricted, and that only three time spans should be available. The argument was that 1 hour is sufficient for consultations, 24 hours is decent if the physician would not be able to inspect the shared data there and then, and one year was for the cases where you wanted to create "permanent" access for your physician. Of course one year is not

truly permanent, rather, it is a long time. The upper limit of one year was so that you would not forget that you created a permanent share and keep it like that for the remainder of your life. For the one year case the user would receive an email notification that the share was about to one-year few days before its due date, with an option to extend. In the last frame the concept of the generated one time code for the HPR-number is shown.

5.2.1 Evaluation in BIE 1

Concept alterations resulting from the first workshop

Support for creating accounts on behalf of others, e.g. children or someone you are guardian for was removed. One of the workshop attendees pointed out that children under the age of 18 have legal grounds for denying parents insight into their medical records, this could have been remedied by lowering the top age for someone you act as guardian for. However, by for instance allowing children above 15 years of age to have and manage their MHB account, you can assume not only that the childlike behaviour of someone under age can affect the quality of the data input, but also a degree of irresponsibility with regards to account safety. It could quite literally be fatal if someone under age had their account password compromised and sensitive documents were to come into the hands of others their age or at their school.

Workshop participants suggested that the app should have an emergency access feature, in case someone was found unconscious. Many different alternatives emerged, ranging from a feature that would set the lock screen on the phone with essential information, such as medical allergies, to having a pin code card in your wallet that could give medical personnel access on site. Many difficulties were identified with these suggestions. Some said that a lock screen with information would be to revealing, and that it would be dangerous if medical personnel became accustomed to only checking the lock screen. Should for instance a lack of information on the lock screen mean that this person did not have any allergies to, for instance, antibiotics? The other alternative with the pin code card was deemed too cumbersome. In addition, the entrepreneur

doctor made clear that chaotic emergency situations usually do not allow for this kind of activity, and other emergency mechanisms for getting this type of information are already in place. Because of its redundancy and unreliability, the emergency access feature was dropped all together.

In general the workshop participants were enthusiastic about the concept, but they were also very keen on more functionality, being in opposition with the idea of keeping the system as simple as possible; their mental model of such a system expected more features, such as graphs, and note taking functions.

Gathering data

Workshop attendees made us aware of a flaw in the interaction logic when creating new documents and taking pictures. The conceptual model of a document, which allows for multiple pages, was designed so to allow for taking pictures of paper documents consisting of several pages. In the first prototype, you would first be asked to take a photo as the first step, in order to minimize steps up until the core action of taking an image, followed by giving the document a name. If this were to be the de facto method of arriving at the camera screen, then it would be a hassle to take several images in a row. Following up on this observation, it was decided that the order of steps would be reversed, so that one first created and named a document, and then added images in rapid succession.

Notes and graphs were also a big topic. In the workshop the users would talk vividly about specialized functions that could let you track and correlate factors, such as food intake and blood sugar levels. The entrepreneur doctor objected that this was in violation with the mantra of simplicity, but eagerness around the subject continued non-the less.

Regarding paper as an artefact and the use of a camera, it was interesting to note that nobody objected to taking pictures of paper. The fundamental action that was core to the project was never challenged. The lack of contest around the subject implicitly legitimized it. The next round of evaluation would cast light on any unforeseen problems of using paper and camera. Some questions were raised about the cost of paper though, seeing how paper printouts at doctors are priced.

Workshop participants on the proposed organizing data

In the workshop, the idea of having five immutable categories was introduced for evaluation for the first time. The idea of immutable categories was conceived by the project team as a means of compromise between patients and doctors. The patients need a sensible way of organizing their documents, and the doctor needs to be familiar enough with the organization so as to easily manoeuvre it.

Nobody opposed the proposed categories, but they did find it lacking. Several other axis of organizing information was proposed. These were tags, searchable annotations and location (where the document was created). Tags represent the option to create a varied taxonomy, essentially furthering the compromise by letting the doctors have their five categories, with an optional and freely defined sub-organization.

Tags were suggested to make it possible to more easily search the documents, as image files provide no meta data of value. Prior to the workshop the research team had discussed the option of using text recognition techniques to scan the uploaded files and identify key words such as "prescription" or "epicrisis" and to suggest an appropriate category and tag based off of the document contents. The team believed, after some debating, that this would intimidate the users, because it made it would give the impression that the system read the contents of the uploaded files. Ultimately it was decided that tags should not be included in the system.

GPS was suggested as a way of automatically tagging documents with the location of where the documents were created, similar to the way images are tagged on the iPhone. However, the images that MHB is meant to store are not bound by locale, as they can be taken anywhere, for instance at home or place of incident. The ambiguity of locale offers no good axis' for filtering or searching.

Sharing your data - what and with whom?

A large part of the concept of MHB is that the accumulated data should be usable for both patient and doctor. This means that the data has to be shared, and the conceived method of doing so was presented to the workshop users in order to discover new areas and unforeseen consequences.

Workshop users were comfortable with the idea of sharing your health book over the Internet, but they had several objections about what should be shared, and with whom they should be able to share it with. Answers given pulled in several directions. Some did not take issue with sharing your entire document portfolio, others wanted a higher level of granular control, sharing as little as just a single document. Some wanted to share their health book with their spouse or children, whilst others only wanted to share with authorized medical personnel. Arguments that were pro sharing everything revolved around patients and their ability to distinguish between "nice to know" and "need to know". On the question of only allowing sharing with medical personnel, the argument for this was that in the form of an example where one could create a share for a spouse, divorce her, and forget that the share existed.

As a middle ground, it was suggested that the de facto model of sharing your health book would be to share everything, but with the ability of omitting certain documents. The proposed method was to have a checkbox in each document that stated "do not share". It was agreed that this should be implemented in the next iteration.

Some users also wanted insight into which documents the recipient of a share had opened, whilst others imagined that it might be stressful for the doctor they shared with if the doctor knew that the sharer had insight into his actions. As a result it was decided that as a minimum the system should let the patient know that the doctor had activated a share using a one time code, but not detail which documents he had opened.

Another issue was the pre-set time and time units available for a share. Participants did not see the reason for this, and wanted the ability to share for any arbitrary amount of time. No objection was held and it was decided that it should be implemented.

Participants also commented that they did not want to enter the name of the recipient, rather just the HPR-number. The system should translate this number into a name. Several reasons were given for this request. The first was that it was envisioned that you don't always need to relate a name a share, for instance for brief ad-hoc encounters at a hospital, where a doctor would be short on time. This way you could just enter a number in the app

and share quickly. A second argument was that adding a name to a share, leaving it for a while, and then revisiting it later could give a false indicator of the doctors existence in the MHB system. It was argued that it would be important that the existence of a recipients name should unambiguously indicate that this user had an account in the system. A third argument was that the HPR number should be tied to a real account, but the system should not disclose whether a doctor had an account or not simply by inputting a number. This could be used for illegitimate data mining, and could put potential doctors off from wanting to use the system. Through these reflections it became clear that the workshop participants expressed much concern for how the doctors and physicians would perceive and use the system. The feedback of BIE 1 prompted a radical redesign of the app look & feel, the design of the web page, and several conceptual changes.

5.3 BIE 2 - Beta version of prototype with focused interview evaluation

The account of this cycle will show the produced web site and the changes to the application. Recapitulating from the previous section, the changes that were implemented in addition to the new design were as follows:

- The ability to create an account on behalf of someone else was removed.
- Take picture and name it as a metaphor for giving input to a new document, i.e. word document, and then saving it was reversed, so that new documents were named and saved before receiving data.
- The name of the recipient in a share was removed, leaving only the HPR as identifying factor.
- The list of available time spans for sharing was changed into allowing any time unit, including permanent shares.
- Taking pictures in rapid sequence for multi page documents
- Ability to mark documents as hidden, omitting them from shares

The suggestions that were proposed but not implemented in the evaluation phase of BIE 1 were as follows:

- Tags - in fear of creating invalid taxonomies that omitted important data
- Thematic categorization of documents (similar to tags)
- Searching - could not be implemented without sufficient meta data, such as tags
- A general graphing function to depict trends - was deemed too complex and confusing, limited value
- A GPS feature that depicted where documents had been created - too inaccurate and ambiguous, could depict the location of incurred illness of place of treatment. Does not clearly identify as a filtering axis.
- High granularity control of sharing, as opposed to sharing everything - omitted for fear of not providing medical personnel the whole picture
- Emergency access, with for instance a pin code card carried in ones wallet - deemed to be of limited value.

5.3.1 Web site front page and about page

The web site has four main areas that the user can interact with. Two of them are of a purely informative nature. The front page that does not require authentication is tasked with describing the project (see figure 5.2), and the about page.

The front page follows a minimalist design with only a few functions. These are a registration form, a button for logging in, an about page and a help page. In addition there are graphics that rotate on a carousel right beneath the menu. The three columns beneath this carousel attempts to depict an anthropomorphic story that exemplifies how you use the health book. The functional purpose of this page is to inform and entice.

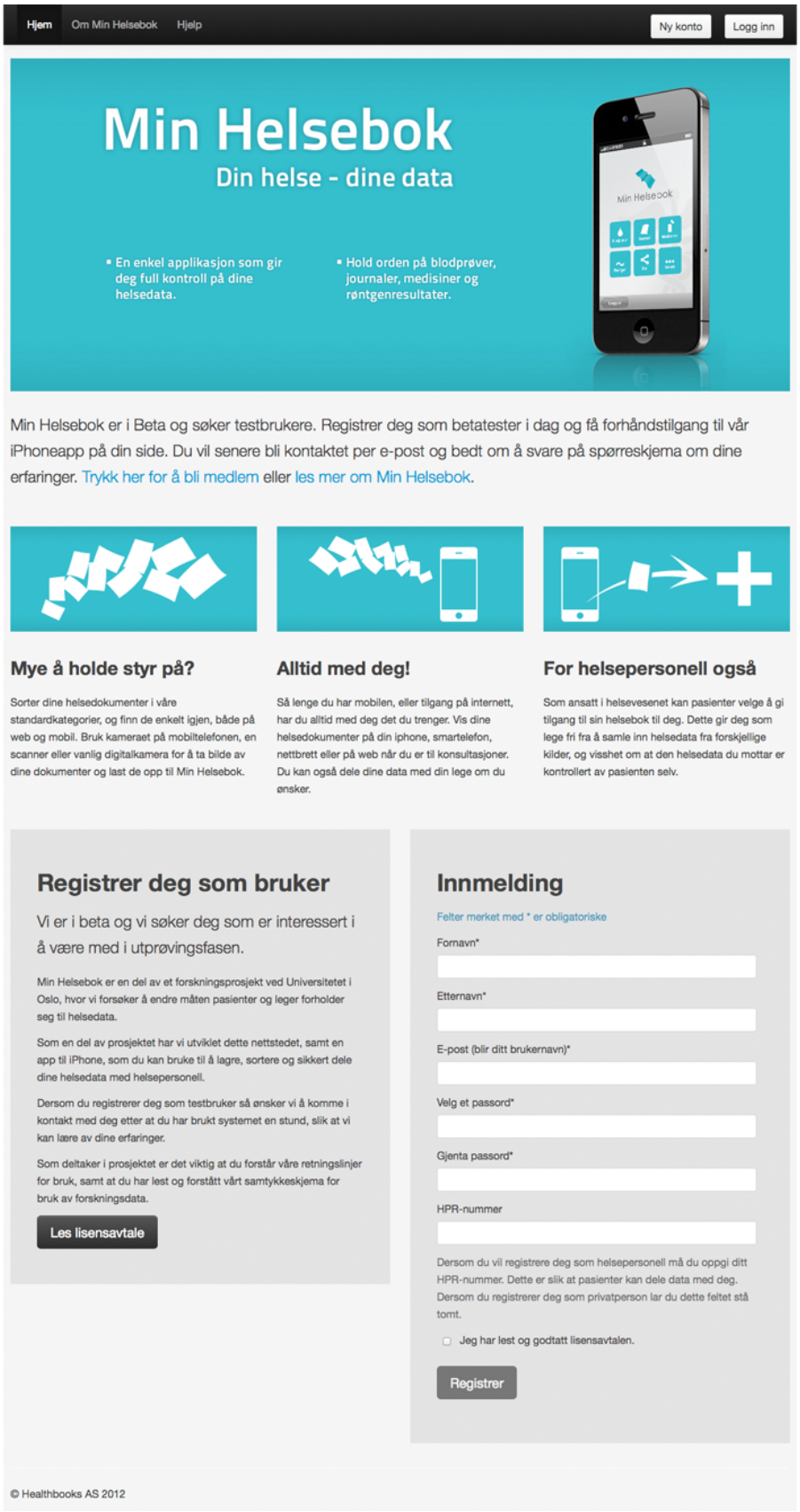

Figure 5.2: My Health Book front page

Figure 5.3: My Health Book about page

On the about page we gathered more detailed information about the project, what it was for and how it worked. We paid particular focus to the idea that the user was in charge of their own data, and that nobody had insight into them without their explicit authorization.

Gathering, using, and sharing data are encompassed in the other two main areas that require users to be logged in, and are demonstrated in the following subsections.

5.3.2 Gathering data

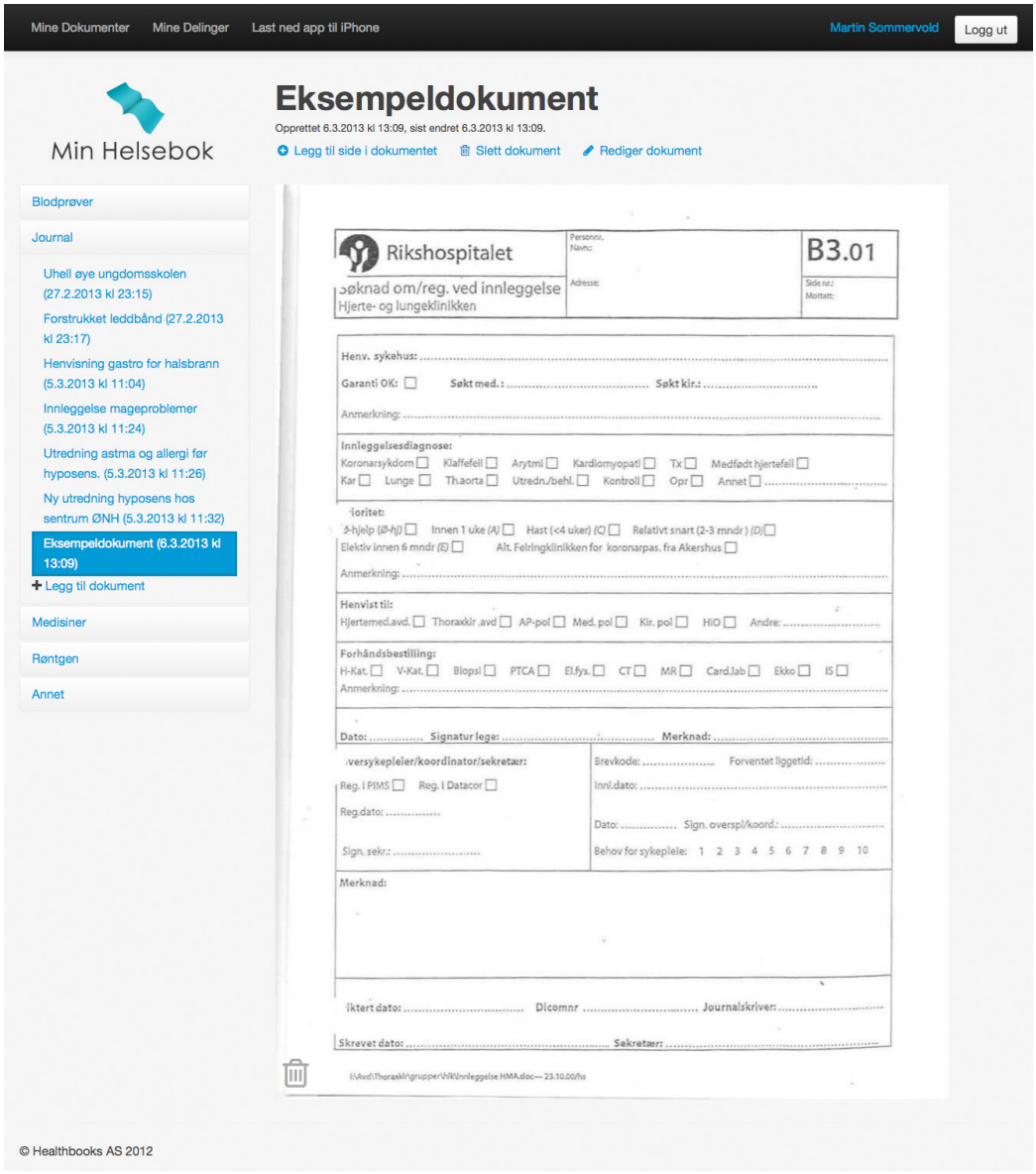

Figure 5.4: My Health Book patient interface

Gathering data and inserting it into My Health Book is done with paper as the information carrier. The user has two choices as to how the data can be imported. The first option is to use a camera phone and take pictures of each page in the document. Uploading can be done with or without the app, as both the app and the website allows for uploading of image files from disk or the camera roll. The other option is to use a scanner and employ the same delivery channels. The web site and app is laid out

to accommodate for the format of a typical A4 page by reserving vertical space for it to occupy. Pictures taken of paper in "landscape" mode are resized to the same width as pictures taken in portrait mode so that the information lines up in a vertical stack. A result of this is that each page in a document can be of variable height.

Once imported into the system the image files are compiled into a conceptual container called a document. The most apt analogy is that of a PDF file where one page comes after the other. The order in which you import the image files dictate how the document is portrayed. Part of the technical specification for the editing abilities in the system was the ability to rearrange the order of the files, but technical difficulties and time restraints kept us from implementing it. For the test users this deficiency was explained.

In the bottom left hand corner of what we have conceptually dubbed as a page there is a trashcan icon. Clicking this lets you delete a single page in a document. This feature is not available in the iPhone app, but would have been if time and resources were available.

In figure 5.4 the main interface for the patient is shown. Inside of each category in the left side menu there is a button at the bottom, "legg til document" (add document). This action prompts the user for a name of the document, followed by the option to add pages to the document.

Figure 5.5: Web site file upload interface

The upload dialogue is fairly standard. It allows you to upload one page at a time, and it provides a progress indicator. The corresponding upload scheme is displayed for the iPhone app in figure 5.6. The upload

formats that the system accepts are jpeg's and png's.

Figure 5.6: Application file upload interface

The mechanisms for creating and editing a document define a conceptual model with which the patients have to relate. Its intentional design was to be similar to the way you create a new document in for instance a word or spread sheet processor. However, from the first alpha, we found that users were not comfortable with the notion of first taking an image and then naming it, as this would hinder them from taking several images in sequence. Rather, they viewed it as more familiar to first create a document, name it, and then input data. This conceptual model depends on the users familiarity and acceptance of this modus operandi (Norman, 2010). This is one of the points that were investigated during the test user interviews.

5.3.3 Organizing data

Depicted in figure 5.4 on the left side is an expandable accordion menu with 5 pre-set categories; Blodprøver (blood test), Journal, Medisiner

(medication), Røntgen (X-ray images) and Annet (other). The user cannot change or add these categories. The categories were chosen based on input from the entrepreneur doctor, introduced in the BIE 1 workshop, and accepted by the attendees. The attendees also requested the ability to create tags and notes, but it was decided that this should not be implemented. A similar organization is depicted in the upper left quadrant of figure 5.7 for the iPhone app.

The remainder of the illustrations in the aforementioned figures depict how documents are listed once a category is selected, options available for each document, and viewing of the document. Inside each category the documents are sorted by upload date, which is shown in the list of documents in each category. This is the only available sorting mechanism.

These five categories constitute the biggest restraint in the organization of documents. Users are free to create documents within the categories, and move them as they like between categories. They can choose to purpose a document as a carbon copy of a document given to them by a medical professional, or they can mix and match. For instance, if they visit several institutions for the same health problem they can create an aggregate of all their documents thematically in one single conceptual document. Documents can be renamed and deleted. Single pages in a document can also be deleted. Documents can also be moved between categories.

These categories were incorporated in two different ways into the design of both the web site and the app. As far as the web site is concerned the number and size of categories are of little importance. Adding or removing a category would simply render a longer left hand menu. For the app on the other hand the categories have been employed in a way that has a guiding effect on the layout of the app. As seen in figure 5.7 the main screen of the app has two rows of buttons. Five of them are categories, and the last one on the bottom right is the button for sharing. This button has a slightly different shape (as a speech bubble, indicating communication).

More information was added to the list of documents as well. In addition to the title of the document, the list now also includes the date and time for when the document was last changed.

The choice of 5 categories was based on two main arguments. The first

Figure 5.7: iPhone application interfaces

was simplicity in a "Steve Jobs" sort of way. The entrepreneur doctor argued that the users would benefit from simplicity, where the categories were dictated by the professionals. The second argument was that this taxonomy made most sense for the medical professionals.

The categories were essentially a simplification of the structure found in the standard used in the EPJ-systems in hospitals and with general practitioners. The rationale behind appropriating this structure was to accommodate for the sharing module, which is designed to remotely share a users entire health book with a medical professional. It was assumed that having a familiar structure would alleviate the need for doctors to organize themselves within a structure wholly defined by the users.

No data analysis is performed on the uploaded images (i.e. OCR) and no metadata besides the filename is attributed to the composed document. Adding a note function for either creating documents from scratch or annotating documents was discussed and dismissed for the prototype. This was done under the mantra of simplicity. Tags were also discussed, but for the same reason omitted. Because of this no search function was included either.

5.3.4 Using and sharing data

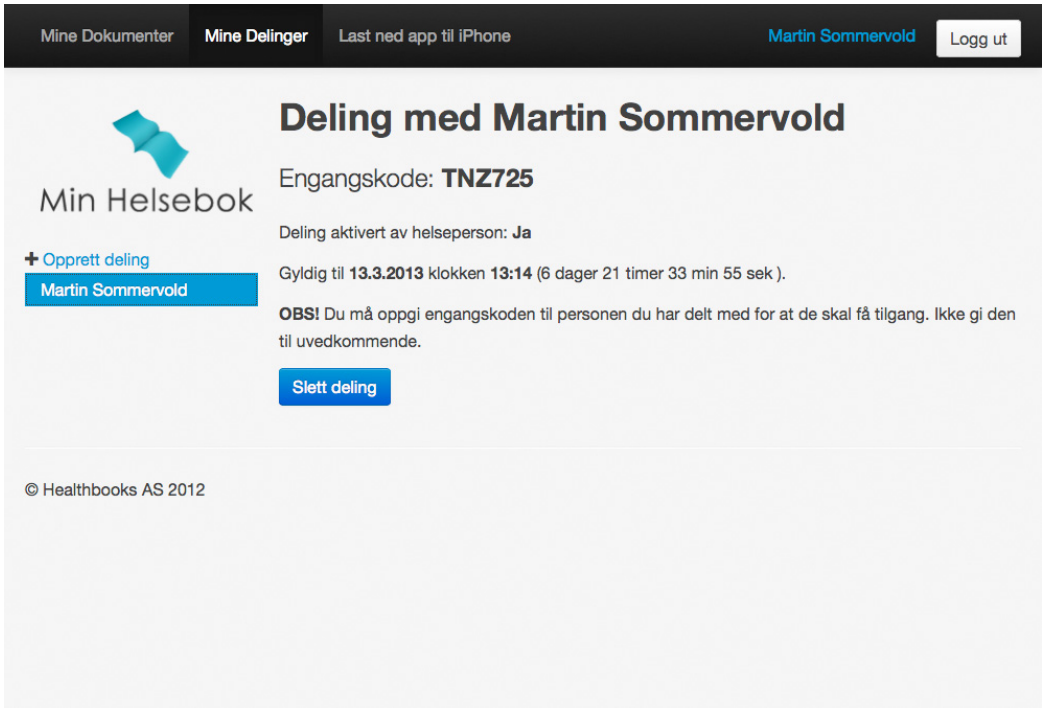

Figure 5.8: My Health Book sharing interface.

The next interface of interest is the sharing module (see figure 5.8). This interface is designed to let patients give access to health personnel. Sharing grants access to all documents in a patient's health book, with the exception of documents that are flagged as "do not share" (not depicted). The patient who creates a share has to communicate the one time code via a side band (different communication channel) in order to complete the sharing. The sharing process involved acquiring a recipient HPR number that all Norwegian authorized health personnel have. This can be acquired by direct communication with the recipient (face to face) or via telephone or e-mail. Once acquired, a share can be created for this HPR number. The recipient will then find this share in a list of "un-activated" shares when they are authenticated as health personnel. In order to activate the share they have to enter a one-time code generated by the system. Once activated by the recipient, the user who created the share can also see that the share has been activated in their sharing interface. They can also see the name of the person who activated the share, and also revoke access at any time. In

addition, each share has an optional time restraint, ranging from validity for 1 hour to infinity (see figure 5.9).

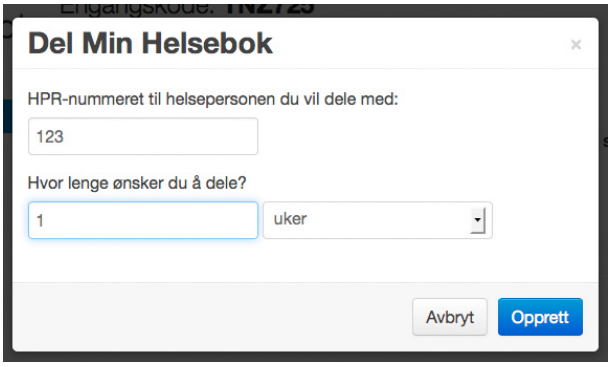

Figure 5.9: Modal for creating new share.

Though cumbersome, the side-band method was a deliberate design. The reason for this method is to provide non-technical user verification. A technical solution would be to use technology such as Buypass or bankID which uses physical number generators and smart cards, but these technologies require proprietary software that runs on java and a tighter integration with health IIs. An app has been developed for the iPhone to provide BankId authentication, but this was not readily available at the onset of the MHB project, and also did not provide the desired flexibility for the data granularity required by the project, e.g. which piece of information would identify recipients of shares. The use of BankID as an authentication mechanism was also referred to as not desirable by participants in BIE 1.

The second argument for not including the aforementioned authentication methods was that MHB wanted to strengthen patient/doctor communication, and by requiring some sort of communication with health personnel you encourage this. The necessary conversation with health personnel in order to convey the one time code could also carry additional information, such as what the recipient should look at and provide feedback on. The interface for activating shares is shown in figure 5.10.

The main interface that health personnel operate within is shown in figure 5.11, called the HPR module. This interface is functionally similar to the main interface that normal users (patients) use. Its layout is somewhat different. The reason for this is that the layout evolved in the later phases of prototype development, and the changes were not implemented in the

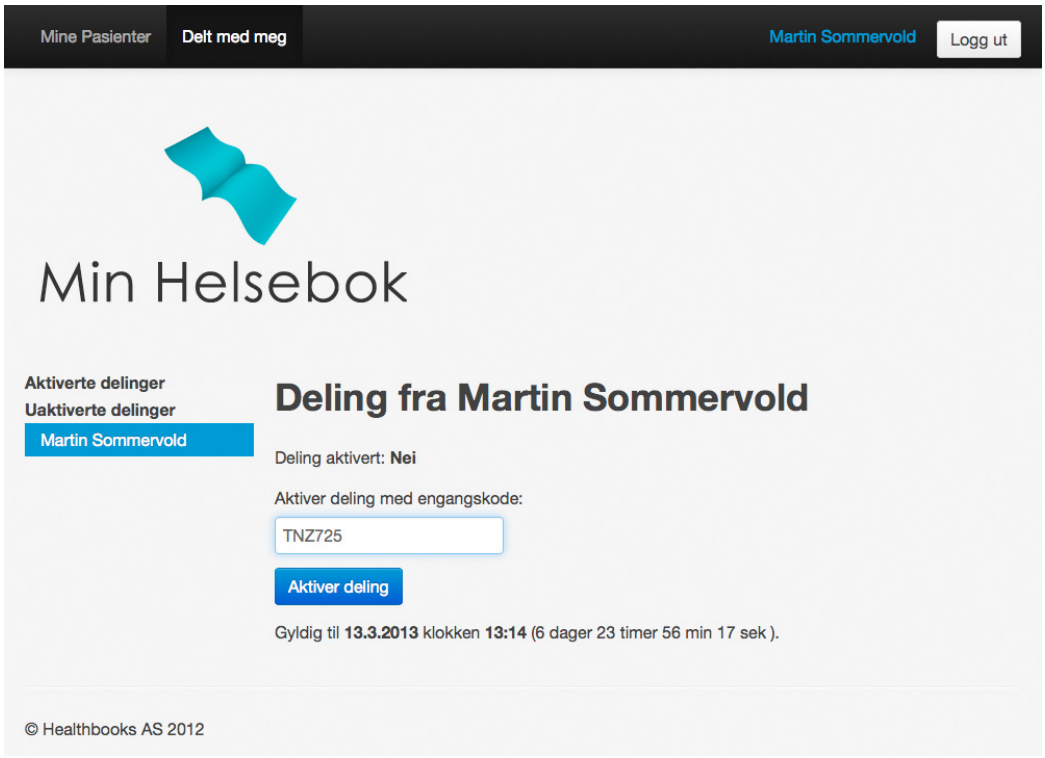

Figure 5.10: My Health Book doctor interface for activating shares using one time code

HPR module. A noticeable difference between the two roles was deemed to be beneficial, i.e. graphically distinguishing between the modes that MHB could be in, which might actually be an argument for keeping it this way.

Using and sharing data with the iPhone app is functionally equivalent with the web page front end with a few exceptions. The web page can run both in a browser on a computer or in a browser on a mobile phone. If it runs in the browser of a mobile phone it provides the ability to upload camera data. In this respect the web site is functionally similar to the app.

For other purposes that are more peripheral to the core functions of MHB the iPhone app has a limited implementation set. On the app you can create a new user account, but you cannot delete it or change your password. For this you have to go to the web page. And as previously mentioned, nor can you delete single images (but you can delete entire documents). This is a weakness that ideally would have been taken care of, but unfortunately we ran out of time.

The lower right button in the iPhone app brings you to the sharing

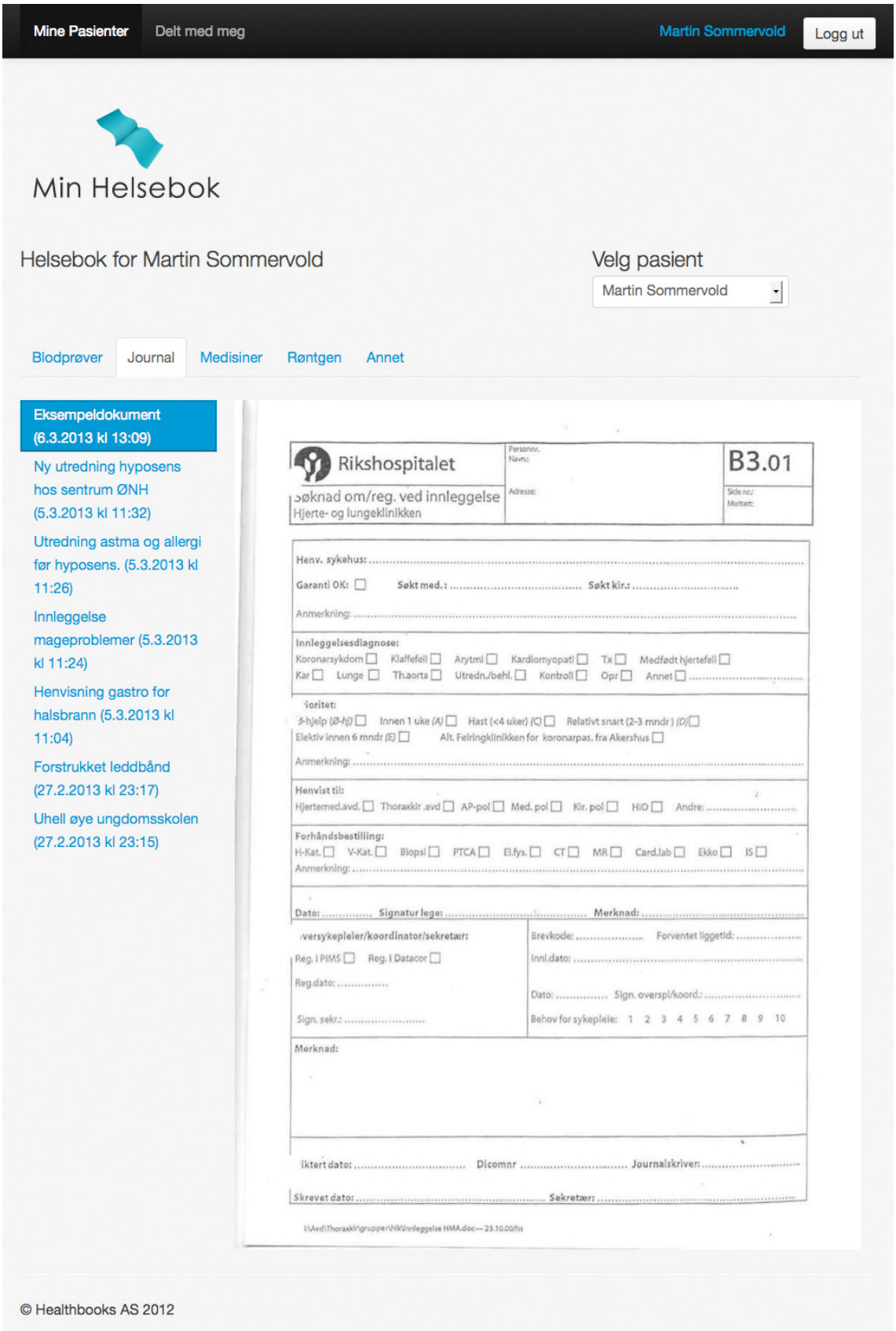

Figure 5.11: My Health Book doctor interface for browsing patients' documents

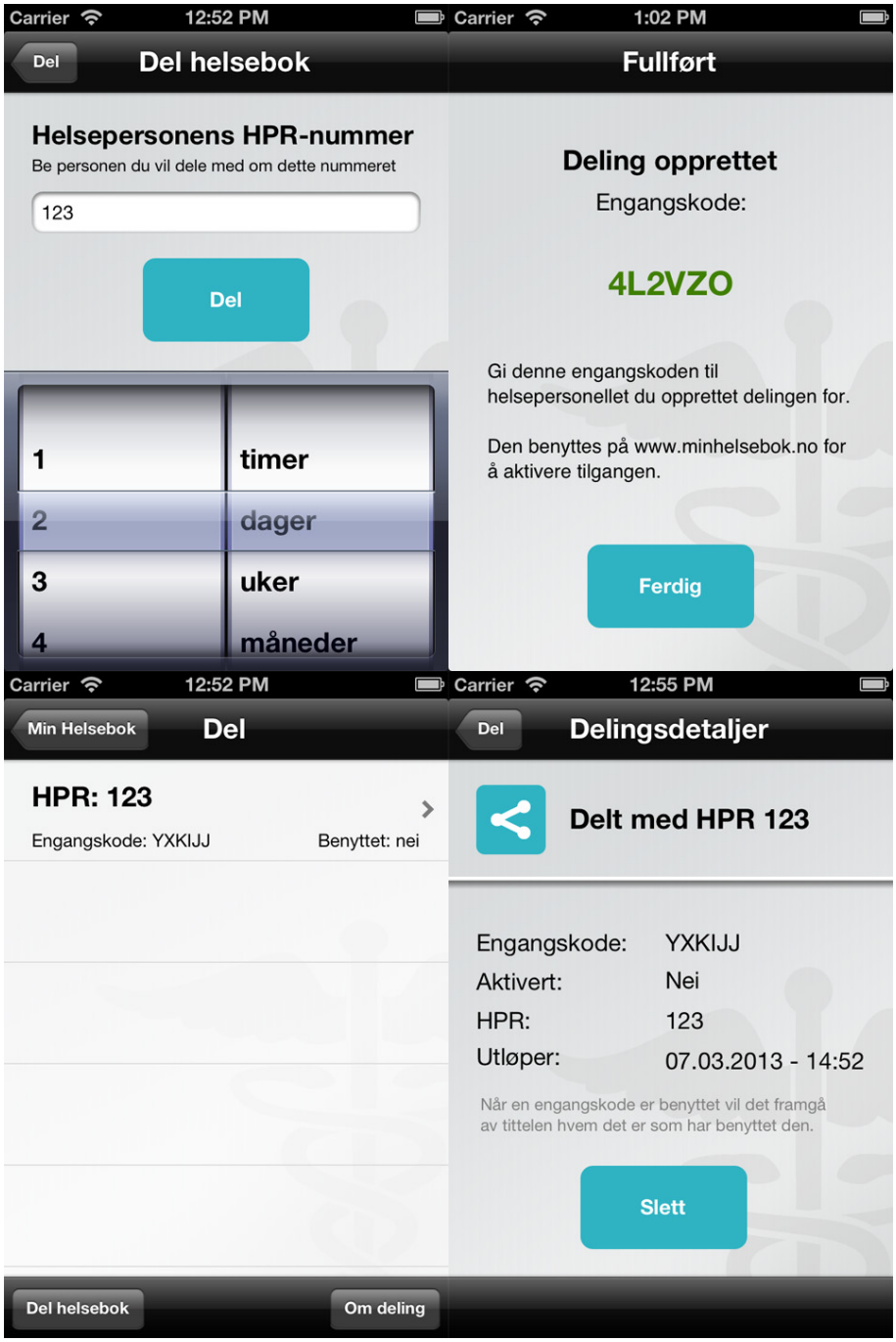

Figure 5.12: iPhone interfaces for sharing your health book

interface (see figure 5.12). It's functioning is similar to the web page, but has a different usage focus. The list of active shares on the iPhone app provides access to the one time code and usage status without having to open the share details. The intention is that the believed typical usage scenario for the sharing part of the app will be during interaction with medical personnel, and identifying pieces of information therefore have to be present regardless of whether the share has been activated or not. Recalling, until the recipient of the share has activated it using the one time code, it will only display e.g. "HPR: 123". Once activated it will display the medical personnel's name. To simplify interaction on site with e.g. your physician, the app will clearly mark the one time code and usage status so that the information can facilitate for and confirm the successful activation of a share.

Finally the share detail view allows you to delete the share. This will immediately revoke access to your health book for the appointed recipient.

5.3.5 Security

The physical locale of the service layer is on a virtual server provided by the University of Oslo. This was important for the project group because of the sensitivity of the data that might end up in the MHB storage. We went to great lengths in order to secure the data that was uploaded. Not running the solution on a shared platform was one of these measures.

This physical architecture also allowed us to implement other security features, most importantly decent encryption. Encryption is resource intensive and several alleviating mechanisms were implemented to ensure adequate performance. One of these mechanisms was image compression before the files were encrypted. Since the majority of files in the system would belong to a particular class of depictions, that is medical documents, image compression and filtering was tuned with this in mind. The result is that upon receiving an image file its file size is reduced by an average of 80 per cent before it is encrypted, which speeds up decryption times when the document is served to the user.

The API also sports a very granular access level management system which is similar to that of NTFS (Wikipedia - NTFS, 2013), which allows

every object in the data storage to receive access rights defined by any chosen verb, such as "read", "write", or whichever verb one might like to define. In the case of MHB this means that each and every object, such as a document, page, share or even user can be asked questions about what a given user is allowed to do with that object. This provides capabilities for fine-tuning access rights and provides protection against data leakage outside of faulty control structures. In short, even if the controllers that shuffle and send data were to attempt accessing a document for which the current logged in user did not have sufficient ownership, then the object itself would halt the process, regardless of how faulty the control structure might be.

5.3.6 BIE 2 evaluation

One on one interactive interviews was used as evaluation in BIE 2. During the interview the test user would be asked to perform tasks, give feedback on them, and sub sequentially also give feedback on the experience and concept as a whole.

Interview testers on interaction and concept

The interviews prompted the users to give very detailed feedback as it allowed them to make comments on not only the concept, but also the interaction with the artefact as they progressed through the interview and accompanied tasks. It became clear in the first interview that a semi-structured approach had to be maintained throughout the interview, as the opportunity for exploration and interaction on part of the tester often caused digressions.

The first taht testers commented on without being asked about was the look of the website. The participants user phrasings such as that the sight looked "professional, sober, correct colours". Besides from being flattering, this was also of importance, as the app and web site was deliberately designed to depict the "sender" as a professional organization. What was surprising though was that the users, in spite of referring to the site as professional, did not gather that the sender was a private organization and

not an official one. In fact this had to be pointed out to them when they commented "but this doesn't feel like a governmental web site, where is the 1996-design?".

All the interview subjects expressed scepticism towards the concept. All of them also expressed that they expected a clear link towards a governmental agency. The lack of this link, as intended as part of the concept, produced more scepticism. All interview subjects recognized the importance of a patient having insight into their own journal, but they did not perceive MHBs solution to be a straightforward, legitimate way of achieving this. A basic scepticism towards storing health data online, with a private company, was expressed by all participants.

In this evaluation session there was also executed one qualitative interview with a general practitioner. The response from the general practitioner will not be emphasized too greatly, due to time limitations in the interview and just having one doctor respondent. Because of the time limitations, the doctor received a demonstration of the system and example usage, followed by a round of questions and comments (interview guide in appendix). The doctor provided very clear response; such a system was only valuable to him if it could save him time. The only context he envisioned that could happen in was during consultation, where a patient could account for a previous consultation that he did not have the notes from, if someone was changing doctors, or coming from a specialist on behalf of someone else's reference. In short, he stated that these cases were few and far in between, and that he did not see the value of such a system. The doctor also expressed concerns about it, arguing that he was afraid it would become fuel for "problem patients", and that the remote sharing feature would be "just another public new management thingy that would instigate even more reporting and scrutiny, without providing any diagnostic value".

The doctor went on to detail how some patients that were frequent users of the option of viewing their journal had become very focused on writing errors that had no implications for their medical condition. He was afraid that mechanisms that furthered this kind of activity would prompt a lot more of this kind of activity, which he viewed as detrimental to the

patient doctor relationship and its basis of trust. He went on to stress that he believed that there were great benefits to a population that were more up to date on their own health and diagnosis, but that the "problematic few" that got hung up on irrelevant writing errors already consumed so much of his time that he were sceptical as to what more activity of this kind might do. Pyper et al. (2004) experienced similar situations in a study with 100 patients that accessed their online medical journals for the first time; they found errors, but mostly related to non-medical errors, the same class of errors that the doctor viewed to be of no relevance. He also added that the cause for these errors typically were because of time constraints and stress, and that more technology that ate into his time would cause even more problems, inspiring a feedback loop that would cause even more errors.

Finally, regarding the interaction with the prototype, the interview subjects that described themselves as being technologically incompetent were the users that performed the tasks with the greatest of ease and fewest errors. They also gave an impression of understanding the conceptual model underpinning the system better, often reasoning aloud in ways that demonstrated correct understanding of the systems intentions and limitations.

Evaluating camera, paper, and the medical journal

As the prototype evolution in BIE 2 had arrived at a high-level functional installation, the users could now test the actual interaction with an iPhone, an anonymzed medical printout, and the upload features on either the phone or the computer.

Using paper and a camera was never questioned or challenged by the participants, very much in accordance with the response given in BIE 1. Some users even described it as "novel, fun, safer". What was meant by safer was that the image as a data carrier was less susceptible to insight than "raw data". The user who made this comment demonstrated technical insight into technology such as OCR text recognition, and stated that "it gives the impression that it will be harder to do a search in my data, assuming that someone gains unauthorized access to the database". In the same breath he also stated that "from an engineering point of view however it would be

interesting to do text recognition so that you can automatically create tags".

The camera interaction was changed as a result of the feedback in BIE 1 so that documents had to be created first and then pictures could be taken in rapid succession. Part of the interaction was a "waiting for picture" screen. All the test users were confused by this screen in one way or the other, and stated that they wanted more immediate access to the camera, preferably directly after pressing "add new page to document". They also suggested that there really was no reason for having just one point of entry for the camera feature, indicating that the interaction was fundamentally lacking.

Organizing data - similar results as in the previous cycle

Very similar to BIE 1, when asked about the five immutable categories, the participants stated that they were okay with the categories, but they wanted the ability to create their own categories, and in addition to mutable categories they also wanted to add tags. Particularly frequently requested was a function that would allow for sorting documents thematically, e.g. "broken leg 2009".

In this instalment of the system the documents were sorted by upload date, which was also appended in the document name in parentheses. None of the users particularly liked this, most referred to it as confusing and irrelevant. Many of the users added the date stamped on the example document in their own parentheses in the document name, leaving them with double dates in the file name, neither of which reveals which is the upload date and which is the incident date.

Functionality for editing and deleting documents and document pages were referred to as satisfactory, but one user pointed out that we had not created logical groupings for tools pertaining to editing of documents. For instance, when viewing documents outside of "edit mode" you had the ability to delete the document and single pages, but these functions disappeared when entering edit mode. The users perceived functions for deleting content to belong under the umbrella term of "editing the document", and so they requested that all functionality that somehow changed or removed parts from the document to be put into the same

screen. They did not state if adding content to the document was perceived as editing the document.

Sharing proves to be problematic

Reponses given in BIE 2 on the subject of remotely sharing, or sharing the health book face to face, was in apparent dissonance with the responses given in BIE 1. In the beginning of this section I gave a small account of the view of a general practitioner, in short stating that he was not interested in remote sharing. As it turns out, the participants in the second cycle weren't either. Participants were sceptical of remotely sharing their health book, and those that stated that they would like to share content with medical personnel exemplified how they would do this in ways that always included face to face contact, typically in a consultation.

From a technical standpoint, several issues were also uncovered with sharing. For instance the users found problem with the use of the HPR number as an identifier for the general practitioner. Outside of arranged consultation scenarios you will have a very hard time getting hold of the intended recipient. Assuming that you want to share with your GP, then you have to deal with phone hours and secretaries.

All the users also stated that they did not want to give out a share to a medical professional for a period of time that extended beyond the time they spent in consultation. In fact, all of them envisioned that they would have continuous contact with the person who was viewing their data, and that the access would be revoked immediately after communication had been broken. That was, if they were to share remotely at all.

A second problem with the idea of sharing was also pointed out by one of the participants, namely that he was afraid of putting too much effort into something like this, because he had no idea if the doctor he was going to see would at all be interested in viewing his health book. He imagined it would be very upsetting to put all that hard work and effort into compiling such an online portfolio, only to have it dismissed by the intended recipient.

Participants were also surprised when they created a share and they received no option of selecting what they wanted to share. "Now what?!"

one of them exclaimed when he arrived at the completion screen for a created share. All the users were upset when they learned that they had shared everything. Only one of them found the "omit from share" button on a document before creating a share, but he was also surprised when he could not select what to documents to share. Suggestions for granular levels of sharing were single document, entire category or tag. The problem of creating a share and forgetting about it was also brought up. Many feared that they would create a share and add something sensitive that they would forget to disclose some time after the share had been created.

The one time code was also confusing. When test participants were presented with the one time code after a share had been created, they were unsure about what they were supposed to do when asked "what happens now?". All of them discovered the solution after reading the entire page, but they felt a bit left in the dark. Several commented that they wanted more narration and guiding, at least the first time they created a share, perhaps in the form of "speech bubbles". They also pointed out that the one time code suffered the same logistical problem of acquiring a recipients HPR number, that is, how to deliver it.

5.4 Prototype concluded

In this chapter I have presented the evolution of the prototype from pre-alpha and through its iterations. The first iteration shaped the second instalment of the artefact, and after what we learned from BIE 1 was implemented (or removed), it was then evaluated with one on one interviews in the part of the cycle I have labelled BIE 2. Feedback has proven to be consistent in some aspects between the two cycles, and widely discrepant in others. The interpretation of the feedback will be presented in the following analysis chapter.

Chapter 6

Analysis

The analysis is structured according to the dimensions of role, implementation, and look & feel in the prototyping scheme. The role dimension is described in relation with patient empowerment theory, the implementation is described in accordance with the IS functionality, integration and a separate section for the sharing feature. The Look & feel dimension devolved into an analytical component of lesser importance, and is not so extensively analysed.

Actions and experience from each research stage are what in sum make out the subject matter of the analysis. To recapitulate, the input to the project were descriptive theories on information infrastructures and patient empowerment, design theory, and the feedback provided by the test participants. Taken together these components shaped the perception and plans of what MHB could and should be, and through iterations of design, intervention and evaluation that were guided and constrained by the input variables we were able to build an artefact for patient controlled health data management.

The challenges that were identified by the participants helped in mapping problems in each of the three dimensions under investigation. These became emergent through a process of coding the participant answers (Crang and Cook, 2007), where iterative cycles through each of the participant transcripts identified roughly 30 themes within the three areas of using, organizing and sharing data. The trends that emerged helped to identify classes of problems, each pertaining to their respective prototype

dimensions (Houde and Hill, 1997). Potential solutions to the identified classes is the output of the analysis, which applies input theories, feedback and team experience acquired from the prototyping cycles. Through analysis the contribution potential of the design, in the form of classes of problems and solutions, is investigated in accordance with applicable theory. The identified classes of problems and solutions are further refined in the discussion section of the analysis, before their final form is presented in the conclusion.

6.1 The role of MHB

At the beginning of the workshop in BIE 1 it was made clear to the attendees that the concept was the initiative and property of a privately owned organization. During the interviews, the ownership form was deliberately withheld from the participants, so as to put them in the role of someone who is discovering and experiencing MHB for the first time. Making a distinction between public or private ownership rendered valuable results, as all the participants in BIE 2 believed that MHB was a part of some governmental, public scheme. Before the participants were told that this was in fact, not the case, they all expressed a large degree of scepticism towards the concept. Scepticism was increased when they learned that MHB was the property of a private organization.

All participants in the interview sessions questioned the motive of a corporate actor. "Will they have insight into my data?" was a question that often popped up. When explained that no, cryptography and organizational routines will make that close to impossible, only one of the participants found the answer to be satisfactory. The remainder of participants made analogies towards for instance Facebook, being very clear on the fact that they understood that Facebook capitalized on the information they put there, and that they were suspicious that MHB would perform the same kind of activities.

Regardless of the scepticism that was put forth by the attendees it also became apparent that the founding principles of MHB was important. Other literature has delved into the effects of journal access and patient

empowerment (see for instance Broom 2005) and identified positive effects of actively engaging in your health data. The perceived importance of the fundamental principles of MHB, that is engaging in your health data, prompted enthusiasm from the participants to delve deeper into the prototype and to provide unprompted feedback, even though they expressed scepticism.

Much of the unprompted feedback arrived in the form of questions, quite often in the form of "why can't I.." or "how can I...". These questions were answered with the rationale behind why the design had evolved as it had, and the idea behind the particular feature they inquired about. The replies that were given to these questions were often met with an air of being unsatisfactory, and the participants would continue with explaining why they believed it should be different.

Many of these replies related to the particulars of an implementation (which will be analysed in the next section), but one recurring themes stood out, namely who the system was intended for. We had marketed the system as being patient controlled, but feedback from test participants showed that the majority of the restraints in the system, in other words the things that *removed* control, were implemented to make life easer for the doctors, not the patient. One example was the immutable and pre-set organization features for documents; they were there not for the patient, but to create a familiar structure for peering doctors.

Design principle number 1 by Hanseth and Lyytinen (2010, p. 9) states that one should "design initially for direct usefulness". This principle consists of four design rules, where two of them are of relevance: 1) Target IT capability to a small group and 2) Make IT capability directly useful without the installed base. The system, as it was designed, was not targeted towards a small group, rather it was targeted against a class of recipients labelled "patients". This broad targeting can be anybody with a medical history. The second rule was violated because the system, as it is intended, and not accounting for any generative capacity, is completely dependant on another installed base, nor was it immediately useful to the test participants.

Violating the rule of initial usefulness rule had a clear impact on MHB, an impact that manifested in the form of over-arching social limitations of

control for the users. In other words, MHB bypassed technical complexity, but experience reflexive social impacts that defined much of the system regardless.

6.1.1 Patient empowerment - what kind?

Vikkelsø (2010) stated that patients who gain access to their journals tend to enter an "editorial role". Ash et al. (2004) found that journal errors are the source of many costly and dangerous problems, and that much of the cause of these errors was due to poorly designed IT solutions. In light of the many mistakes found in health records, the editorial role is warranted and legitimate, but that does not mean that getting to proof read your journal is synonymous with patient empowerment.

From an interview with one GP it was stated that some patients are "problem patients" who get very focused on journal errors. Some errors are simple writing mistakes, other are misrepresentations. According to the doctor, an entry cannot be deleted, but it can be overruled by a new correcting journal entry. From his point of view a new and correcting journal entry is more than sufficient for the purpose of maintaining high quality medical care, but the patients could be adamant that the entry should be deleted, even though the doctors IS did not allow for deletion.

Through examples of "problem patients" it was clear that the GP, as he expressed himself, spent quite a lot of time on managing small fires of what he perceived to be of very limited medical interest. Even though mistakes in health records do occur and do have real life consequences in many cases, the solution to the problem might very well not be to task the patients to correct for faulty IS design. Rather, the design flaw should be remedied, and patient empowerment should provide a kind of value that has higher medical relevance. A class of problems can be derived from the view and experience provided by the GP, the many errors that can be found in health records (Ash et al., 2004) and patient trends of largely focusing on writing mistakes (Vikkelsø, 2010) : what kind of patient empowerment should a patient controlled system provide?

In addition to inspecting and correcting journal entries (which you can do without an IS such as MHB), one type of power is the power to

take control over the flow of data. If a patient recognizes the problem of information flow between health care institutions, she can opt to take control of the process. Providing tools that ease transport and provide secure and reliable access to documents is thus empowering. However, empowerment in the form of control over transport of data is not void of challenges, nor does it seem sufficient to qualify for the label of patient *control* in the eyes of the test participants. These challenges will be discussed at the end of this chapter.

6.2 Implementing a narrow set of functions for a complex problem

Conceptually MHB was envisioned as a solution that was to be as simple as possible. A mantra of simplicity through limited functionality was established and consequentially guided the design of the prototype. Respondents in both BIE cycles requested additional functionality, such as notes, annotation features and graphs. Asking for such features has also been the trend in other studies, such as with Enquist and Tollmar (2008), outlining a trend towards wanting more functionality, not less in patient centred systems.

6.2.1 Functionality

The common denominator between the participants in either cycle was that they indicated that the offered set of functionality was too narrow. The implementation as it was when presented in BIE 2 got a lukewarm reception. Enthusiasm only seemed to arise when participants expanded on the concept with their own ideas.

The mental model we had envisioned was implemented correctly, but only in the sense that all participants figured out how to use the system fairly easily, and that the systems design and presentation communicated how it should be used. However, what we intended was not in harmony with what the users expected. Users experienced confusion when they found that the system did not cater for their expectations, a situation that is

analogous with the example of the TV remote control. The functionality of the system was overly simplistic, making it more complex for the end user when they expected to be able to do more than the system offered.

Information in MHB had an imposed structure. It had so in two ways; by format and by categories. Users wanted other ways of organizing and searching through their documents, arguing that they had too little control. They found the organization of the information and the surrounding functionality to be of little value. This feedback uncovered that the concept of control was not a term one should assume to be unanimously understood. For the designers of MHB, the control concept was understood to be the ability to exercise power over the transport and sharing of information. This understanding of control was not very well received by test participants, who argued that control also meant the ability to control the data through various means of categorization, and also other types of data sources. They also understood themselves as creators of data, exemplified by the requests to input and display data in graphs, and to create notes.

All the suggestions by the test participants would increase the generativity (Zittrain, 2008) of the system, but they would also create tension between the two intended target audiences. This tension is mediated by the means of integration within, to and from MHB.

6.2.2 Integration

As a premise for even existing, the MHB system relied on not being technically integrated with any other systems. I previously argued that avoiding tight couplings with any established II was paramount in order to reduce complexity and avoiding its associated dangers of creating the unmanageable. The complexity problem was perceived to be the reason for the problems in existing health IIs.

Achieving an IS that is truly decoupled from an II, at the same time as it relies upon data from said II and further interaction with its socio-technical surroundings, is quite simply impossible, especially within the understanding of actor-network theory (see especially Callon 1986), which the notion of reflexive modernization and its concept of side-effects build upon (Hanseth et al., 2006).

The designed method of minimizing technically coupled interaction, so as to avoid its accomplice complexity, was by interaction via paper as a gateway. Paper turned out to be the least controversial feature of MHB. Several testers stated that they liked it, in addition to accounting for their perceived rationale behind using paper, which was incredibly similar to the rationale put forth by the researchers and the entrepreneur doctor; that health IIs are complex, and paper could be a way out of the grip of the complexity. However, paper as a gateway has not been entirely unproblematic. Paper journals cost around one hundred nok per printout, and are a barrier that limits the ease of use of the system.

In addition to the envisioned way of using MHB by project team, MHBs potential for expansions was also contingent on how the system integrated. As MHB aimed to serve two masters (doctor and patient), it would have to negotiate potential conflicts of interests between the two. It did so by serving only a limited set of functionality to either party. As soon as ideas of adding onto MHB with features such as notes or graphs, questions of not only "how will this bring value to the user" popped up, but also questions of "how will this create conflict". Because tension introduced complexity, and the team was set on keeping it simple, then the concern of how to resolve tension was solved by not introducing new features at all. The potential for conflict was guiding in many design decisions, and it was almost always mediated by the functionality to share the health book.

6.2.3 Sharing

In the evaluation phases of the 2nd BIE cycle the users indicated that they did not want to use the technical possibility to remotely share the contents of MHB. All the participants in BIE 2 wanted face-to-face contact, so that they could exercise greater control over how their data was being used.

Sharing was the most controversial feature of the project. Technically, the sharing module of MHB is devised in accordance with II design rule 4 design for one-to-many IT capabilities (Hanseth and Lyytinen, 2010), in contrast to all-to-all capabilities. Illustrated, the sharing module lets one patient share to many medical personnel. With the case of MHB it becomes clear that the existence of such capabilities does not guarantee that they

will be used.

The technical implementation of the sharing module made several presumptions about patients' ability to communicate with doctors. It did not consider the barriers of remotely achieving contact with a physician, which the test participants pointed out. Using a side-band method of conveying one-time access codes is dependent on being able to reach whoever you want to communicate with. Doctors have very limited means of being reached through other channels than appointments and memos from secretaries.

Another envisioned usage scenario was to give access to a physician during a hospital stay. For sanitation reasons it is preferable to remotely share MHB to an attending physician over handing over your phone to display a health record. It was believed that for this reason, and to provide flexibility for the physician, it would be important to be able to quickly share, e.g. by only implementing the HPR-number as the identifying factor for sharing. However, the concept of sharing was so lacking in many respects that the perceived (or maybe even assumed) value of sharing remotely was dwarfed by the challenges and constraints that the feature reflected back on the system as a whole.

Sharing granularity was also a big issue. MHB shared everything except that which you had marked as private. Test participants wanted a lot more granular control if they were to share at all, and when asked if they would use sharing if document-level granularity was implemented the reply was usually that they probably would not share remotely. It was not a matter of how much you shared, it was a matter of not wanting to lose control of what happened to any kind of data, regardless of the granularity of what was remotely shared.

Taken together, the functional aspects of MHBs implementation and integration form the basis of a class of problems; how should patient controlled solutions be designed, and towards which end? Again, this question appears to be very broad, but as the experiences from MHB show, there are a few very clear guidelines and inherent properties of something labelled as "patient controlled" that should be taken under careful consideration when attempting to solve a class of problems that

addresses the intended result of empowerment.

6.3 A look & feel for a corporate or governmental sender?

During testing in BIE 2 it became clear that there was a miss match between the design of the service and the expectancy of what MHB was. The phrase "where is the 1996-design?" from one of the participants really captured this miss match between who they believed the sender of the system was (described as a governmental agency), and who the design was meant to depict as the owner of the system, i.e. a private organization. When asked who they believed the sender was, all participants gave replies along the lines of "government", or "public service".

Who owns the system is important, because the expectation effect, in this case manifested in the form of "expecting a stereotypically messy government website", instilled a sense of cognitive dissonance (Falvo and Urban, 2007) between the belief that the sender was a government agency, and the perception that this design does not match the expectancy of what a system owned by such an agency should look like. A state of cognitive dissonance is a psychological instigator of action, inducing a strong need to alleviate the discomfort it introduces by means of some the available options, usually the one that offers the least resistance (removing oneself from the situation). Participants identified the contents of the intended communication behind the choice of colour and layout, i.e. to communicate professionalism and something other than your "typical health web site". The intention of the design to identify MHB as a private initiative failed.

The instilled dissonance as a result of miscommunicating the senders' identity opened the door for the participants' thoughts on how comfortable they were with putting their data into the hands of a private organization. No apparent solution was offered by the participants, but they did discredit the approach of communicating that MHB was a private initiative through the use of graphical elements that would portray the sender as "not government". The look & feel aspect of the design suffered from communicating a message that did not harmonize with the expectations of

the users.

6.4 Discussion

In this section I will refine the classes of problems as identified through the analysis, propose classes of solutions, and discuss the conditions behind each normative contribution that this thesis makes in the form of design guidelines for patient controlled systems.

6.4.1 Patient empowerment

Control and empowerment are two very broad terms. As the analysis divulged, the two terms have widely different meanings for a wide variety of users. Kushniruk and Turner (2012) showed that the user group that one loosely can address as "patients" is enormously heterogeneous. Because both patients and doctors were the intended recipients of MBH, not only does the question of who to design for emerge as a class of problems, but also towards which end value, and for whom the end value should be achieved. The first proposed class of problems for the concern of what defines a target audience emerges as:

Who should patient controlled systems be designed for?

At first glance this question appears to be tautological, but following that the user group referred to as "patients" is very heterogeneous, a state which has proven implications for their aptitude towards interacting with MHB's class of systems, then it is in fact not clearly given who a patient is. This class of problems involve identifying specific user groups who match the definition of a patient, separated by dimensions such as gender, age, social relations and type of illness.

Table 2, which compared existing solutions, illustrated that common to many other patient empowerment initiatives were the fact that they had specific disease functionality. I argue that disease specificity is sensible in the sense that they target a sub-group of the term group of "patients". Targeting a sub-group, however, does not necessarily imply that one should

create very specific solutions for very specific conditions. On the contrary, overly specific solutions can become very complex and costly, and with limited value in the sense that they only target a small potential of the possible users. Rather, MHBs class of design can be made available to many kinds of patients by understanding the concepts of control and power, and employing suitable mechanisms for putting them to life in a generative fashion.

Still, many different test participants had many different reactions and ways of understanding MHB. They all perceived various degree of value from the proposed system. As such, the category of "patient" is still valid as an answer to the class of problems under question, however the problems the various users and the process of evaluation uncovered warrants a better understanding of the term patient.

For instance, age was a factor in what defines a patient, illustrated when valid concerns were raised over the effects and safety of giving control to an adolescent, who has various degrees of rights to decide over her own body at different ages prior to becoming an adult. Given that adolescents are prone to make poor judgment calls on matters concerning their health and the information surrounding it, then it follows that they should not be given extensive control of their health data in an IS that facilitates for sharing, and which also is highly available through an online service. Adolescents have limited decision control up until they reach adulthood for a reason, and thus it wouldn't be appropriate to extend an offer of control to an adolescent through an IS that goes beyond the actual decision control they possess.

As illustrated, the concept of control is not readily defined. Control is guided and shaped by several factors, age being one of them. Another aspect of control is that it relates directly to power. To give someone control is to empower them, as in giving them the power to gather, change, organize, create, transport and utilize their health data at their own discretion. To remove or restrain these abilities is synonymous to removing control, the opposite of what the term patient controlled promises. The legitimate limitations one can impose on a patient controlled system should therefore not extend beyond restricting access for those who otherwise

do not have the corresponding control (power) to appropriate health data outside of the IS. In short, this excludes everyone except responsible adults, and following this argument the solution (COS) to the previously stated class of problems (COP) is:

> Patient controlled systems should be designed aiming for a high level of privacy with a low level of imposed control for responsible adults.

This COS is quite broad, and appears in the form of a guideline for how the role of a patient controlled system can be perceived. However, it also has more specific implications. For instance, not imposing a lot of control over what the user can do with an IS involves that one should limit the introduction of elements that reduce and limit control, such as tensions between user groups. The most prominent such tension is a result of the sharing module.

Another important aspect of this COS is that in the act of not imposing control over someone through overly simplistic solutions, one does the opposite. That is, with no imposed control one has great liberty and control, but control requires responsibility. This means that, implicitly, a patient controlled solution does not cater for everyone. By necessity, a system that offers more complex functionality than in the current instalment of MHB, puts greater demand on the user. This means that the system is no longer appropriate for "aunt Olga".

The realization here is that those that are not capable of using an IT system for storing and sharing health data, are likely to be the same people that need to be better taken care of; In other words, those who control *should* be imposed on. As it is with many realizations, once they are made, they seem fairly apparent. Regardless of how such a realization should have been made, the fact that patient controlled systems are not for everyone has profound impacts.

This impact hinges on the fact that control is power, and if MHB does not offer sufficient control, than it is in essence taking away power, i.e., it is not empowering. In order to be empowering it needs to offer more control, but this means added complexity. Added complexity is not for everyone, as

it requires more skill to operate. If more complexity is marketed as "simple to use", then MHB runs the risk of luring less skillful and vulnerable users into the system, the very users that perhaps should not be given more control. If less skillful, vulnerable users do not master the system, then not only has MHB not empowered them, it has disempowered them. Patient controlled systems must deliver what they promise, and what they promise is not for everyone.

6.4.2 Functionality and Sharing

Limitations imposed by the sharing module are anchored largely in the social issues of communication and role. For instance, doctors have to acknowledge the value of a patient that shares data with them, and it also has to not impose itself as "another new public management" thing. Unfortunately that is exactly what MHB does, as MHB demands that the doctor relates to it in a very particular way, within a time frame they do not control, and with automatic and un-transparent mechanisms of reporting back to the patient if the demands imposed on the doctor have been fulfilled.

Having arrived at an understanding of control and empowerment, and how patient control is negated by targeting MHB towards both patients and medical personnel, it becomes arguably beneficial to reconceptualise what kind of functionality a patient controlled system should entail, how it should be implemented, and how it should relate to medical professionals.

If the backlash of attempting integration with limited technical elements occur in the form of social tensions that have a negative, reactive effect on functionality is the norm when targeting for two recipients with discrepant interests, then at least the idea that IIs are socio-technical entities appear to be valid. This is of course, no big surprise; technically problematic solutions to social problems are not solved by bypassing the technical implementation.

Acknowledging that social elements have had a very guiding effect on MHB, and that control is mediated through social factors, one can thus claim that if one wants to create a truly patient controlled system, one must avoid the introduction of socio-technical elements that severely negate

the ability to exercise control with a set of given functions, in addition to avoiding the introduction of elements that do the same for future, as-of-yet unplanned additions to the system.

Problems of tension rose from attempting to arrive at value from introducing similar functionality to two target audiences that have conflicted interests. The problems manifested both technically and socially. From these experiences the following problem class can be formulated:

> How can patient controlled information systems be designed in order to provide high and relevant value for the patient?

A proposed solution to this problem is the following solution class:

> Patient controlled systems should avoid the introduction of socio-technical elements that negate patient control, such as several target audiences with conflicting interests.

It would of course be up to the reader to arrive at the finer points of this guideline, but to demonstrate its validity, it's implications if deployed in the MHB project would be to recognize that not only does the system have the need for an input of a socio-technical nature, which we attempted to solve (quite successfully) with the introduction of a gateway, but also that the gateway would have to funnel and translate social elements in *both* directions between patient and medical practitioner.

To clarify, MHB would have to recognize that paper as a gateway to bypass technical complexity is insufficient. The gateway would also have to deal with the social implications of not only gathering data, but also using it. One possible, and in my opinion likely contingency for success, would be the removal of the sharing module all together. Removing remote sharing would force the users of the system to utilize it in a face-to-face, non-time shifted context. It would also remove a large portion of the restrictions on what kind of functionality the system could offer for the patient, in essence allowing the system and its designers to focus on making and delivering what the term "patient controlled system" promises.

6.4.3 Look and feel

The "build it and they will come" fallacy was a mentality that the project team was aware of and made plans to avoid. The system did not attract any significant number of users. Without conducting a proper market research scheme, the reasons as to why MHB did not gain any traction will be speculation. However, MHB is an unusual project, with novel components, context and governance with which the public is unfamiliar. From the feedback sessions in BIE 2 it became clear that the look and feel of the project did instil a sense of professionalism and seriousness, but this was not what the users expected from what they thought to be a public health organization web site.

It is important to recognize that the context of MHBs class of systems is not usually grounded anywhere outside the hold of public institutions. The combined effect of a patient controlled system as something novel, with the novel approach of running the project and system as a private company, is a state that should be clarified for the potential users. The backing argument for this "should" is that the test participants expressed scepticism towards the concept before they knew or understood that it was a private initiative, and this scepticism was increased when they learned that this was the case. Test participants expressed that they did not readily trust a private organization with their health data.

Clarity is important, not only with regards to what kind of functionality the system offers, but also who offers it, where they are positioned, and how they profit from the system. The problem of communication thus becomes how one can design so as to communicate, with convincing clarity what the system is, who runs and owns it, and why they do so. Through the evaluation of the look & feel of the website, the following guideline is proposed:

> Patient controlled systems should be designed with expressive and explicit arguments, aiming to communicate with convincing clarity what the system offers, who offers it, and what their agenda is.

This design guideline, if applied to MHB, would prompt a refactoring

towards focusing more on who the sender of the system is and how the sender benefits from user participation. The argument for being expressive is found in the observed confusion of test participants. They were all exposed to contents that explained the project to be a private initiative, but it was not communicated effectively enough (i.e. not expressive enough). Ways of achieving better expressions are many, and context sensitive, but as a general rule that which should receive most attention should be placed at highly visible and often observed locations, with high contrast (Falvo and Urban, 2007).

The second element of the design mantra, explicit arguments, come from the observation that test participants, whilst expressing that the system "felt professional", expressed that this instilled discomfort. I have argued that discomfort could arise from a state of cognitive dissonance (Falvo and Urban, 2007), which can be induced from confusion. By being explicit, e.g. by relying on expressive textual arguments over vague graphical elements to convey a message, one can eliminate confusion as a source of cognitive dissonance. Being explicit will not guarantee that discomfort and distrust is removed completely, as there is still much potential for disharmony between attitudes and beliefs for an IS that aim to work with sensitive health data.

6.5 Analysis concluded

Several classes of problems and solutions were arrived at in this analysis, each pertaining to the three prototype dimensions. Analysing the role dimension revealed that patient controlled systems are novel, and so is the notion of private governance for a system such as MHB. Test participants recognize the importance of the principles that MHB was built on. These principles were the increased control over ones health and care trajectory through empowerment. However, even though the principles were perceived to be of high importance, test participants were explicitly sceptical towards uploading their health data to a private online service.

The analysis also described control and power as explicitly connected.

The power to better your health care is facilitated by the possible actions a user can perform, such as decide how their health data is used, stored, organized and shared. A reduction in control over these elements was perceived as a reduction of power, the opposite of what a patient controlled system promises.

To prompt for reflection on the behalf of designers of patient controlled system I posed the question *who should patient controlled systems be designed for?*. I argued that even though it appears as tautological (the answer is in the question), it does force one to consider what defines a patient, and following such a reflection also arriving at what the legitimate constraints are that can be imposed on a patient in what is branded as a patient controlled system. My conclusion was that the only legitimate constraint should be that the user is an adult and legally able to represent herself.

Test participants replied that MHBs implementation imposed control over them beyond what they regarded as legitimate. They argued for mutability of categories, the ability to upload different file formats, and to create their own data. The identified the ability to remotely share the health book as the culprit of the illegitimate constraints over their control within MHB.

The problems with sharing that test participants identified were that they wanted better and continuous control over how their health data was being viewed and used by others, and that conveying one-time access codes or acquiring doctors HPR-number via a side band was non-trivial. Remote sharing proved to be problematic, unwanted by many and also the cause of the many of the restrictions and tensions in the implementation. These conclusions were the basis for a problem class of *how can patient controlled information systems be designed in order to provide high and relevant value for the patient?*. The guideline I produced as an answer to this problem class was that *patient controlled systems should avoid the introduction of socio-technical elements that negate patient control and introduce control tensions between target audiences*.

The look & feel dimension of the prototype received less focus throughout the project, as the only big perceived challenge was the representation of the sender and the expectation of who the sender was.

Some interaction problems, such as button sequencing for taking pictures, were identified, but were perceived to be of lesser importance for the analysis, as they could easily be fixed. A design guideline was proposed for the look & feel dimension that aims to minimize the representation challenge: *Patient controlled systems should be designed with expressive and explicit arguments, aiming to communicate with convincing clarity what the system offers, who offers it, and what their agenda is.*

I have in this analysis arrived at design guidelines for each of the three prototype dimensions that were explored. The guidelines all apply to the instantiation of an actual artefact, thus placing them on level two of the design science research contribution types as put forth by (Gregor and Hevner, 2010). This placement categorizes the guidelines as not too general, nor too narrow in terms of how they can be applied. Designers of information systems can apply and understand the guidelines in many different ways, but their specificity locks them to the context of patient controlled HIS.

Chapter 7

Conclusion

The motivation for this thesis was to create a novel artefact that would explore and find new ways of using patient health data in an information system that were controlled by the patient. It investigated the possible solutions that the appropriation of paper as a gateway offered. Many different patient controlled initiatives of various and similar kinds have been conducted previously. A sample of these initiatives were presented and compared in chapter 2, through which the novel components of My Health Book were identified at the same time as recognizing that the initiative was not wholly unique.

The research design was conducted in stages and adhered to the action design research methodology. First it utilized input in the form of theories on information infrastructures, patient empowerment and input from project participants (both designers and testers) in order to produce an understanding of the problem domain, and a rudimentary prototype that was used as a primer for the prototyping stage. The second stage, prototyping, was conducted in iterative cycles labelled BIE (build, intervene, evaluate) and investigated the prototyping dimensions of role, implementation and look & feel. The last stage was the analysis of the prototype, which produced design guidelines for each of the dimensions.

The prototyping build phase produced a high fidelity, high-resolution prototype of a web site and an iPhone. Data was gathered through test participant feedback in a workshop and in one on one interviews. The workshop and interviews formed the intervention phase. Evaluation was

conducted both during and after the design process, where the evaluation process negotiated the relationship between the input theories, the limits and possibilities they defined, the feedback from test participants and the applied knowledge of field experts on the design team.

Results from the building and evaluation of the prototype emerged under each of the prototyping dimensions. For the role dimension a guideline stating that *patient controlled systems should be designed aiming for a high level of privacy, with a low level of imposed control, for responsible adults* was produced. The word role is never explicitly used in this design guideline, but the guideline is formulated so that its application produces an IS which serves just patients, clarifying that the role of a patient controlled IS should be to empower the patient. Empowerment is contingent on control, and control is negated when others than the patient herself are served by the IS.

For the implementation the proposed design guideline was that *patient controlled systems should avoid the introduction of socio-technical elements that negate patient control, such as several target audiences with conflicting interests*. This guideline was based on the experience that the majority of functionality in the implementation that was purposed towards increasing patient control did not deliver as promised. The ability to remotely share with medical personnel imposed overarching restrictions on all current and future functionality.

The look & feel dimension received less focus in the evaluation of the prototype, focusing mainly on the problem of communicating clearly who the owner of MHB were and what their agenda was. Recognizing that test participants scepticism towards a privately owned patient controlled HIS increased once they learned that the system was, in fact, not a public initiative, prompted the formulation of a design guideline. This guideline stated that *patient controlled systems should be designed with expressive and explicit arguments, aiming to communicate with convincing clarity what the system offers, who offers it, and what their agenda is*. The guideline recognizes that MHBs class of systems in a private context is novel and unusual, a situation which cannot easily translate into trust towards the system on behalf of potential users. Rather, the guideline aims to reduce the chances of producing a situation where the system owner is confused, a situation

that produced discomfort and distrust, thus lowering willingness to use My Health Book.

As is with any sizeable study of any subject, the research process will always deviate from the best-laid plans and intentions. This study intended to include a much wider sample of test participants, especially amongst prospective users that had complex medical issues. Unfortunately, the project was unable to attract any significant number of test participants, and many of those who participated in the testing were young adults in good health. The representativeness of the test participants therefore posed limits on the study of MHB, such as not being able to study how chronically ill could use and find value in the system over time. A future, more lengthy and longitudinal study of MHBs, including long term patients, could provide much valuable knowledge for the understanding of patient controlled system. None the less, the design, effectuation and study of My Health Book has yielded interesting and valuable knowledge of what a patient controlled health information system both can, should, and should not be.

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Appendix A

Interview guide

Brukergrensesnitt

- Får du tilstrekkelig informasjon om systemet før og under bruk?
- Er det klart hvilke valg du kan gjøre?
- Er det klart hva konsekvensen/effekten av disse valgene blir?
- Fungerer det greit å navigere (gå fram og tilbake mellom de ulike funksjonene) i systemet?
- Er menyvalg og knapper presentert på en forståelig måte?

Funksjonalitet

- Er det enkelt å opprette en bruker i systemet?
- Er det enkelt å laste opp den informasjonen du vil lagre?
- Er du fornøyd med mulighetene til å slette, redigere og flytte informasjonen du har lastet opp?
- Er det enkelt å dele din informasjon med andre?
- Finner du at sikkerhetsnivået er tilstrekkelig?

Hvordan har du brukt systemet?

- Hvilke utfordringer har du møtt når du har brukt systemet?

- Prober: Har du støtt på noen utfordringer som ikke er relatert til selve systemet? F.eks i forhold til anvendelse sammen med lege?
- Kan du fortelle om hvordan du har benyttet min helsebok?
- Prober: bruker du web eller mobil mest? Hvorfor den ene framfor den andre?
- Hvordan opplevde du relevansen av dokumentene du fikk tilgang til fra din lege for deg som pasient?
- Prober: lærte du mer om din egen helse? Har du delt dokumentene med andre helseinstitusjoner? Forstår du dokumentene du får utdelt fra helseinstitusjonene? Burde de være enklere å formulert?
- Hvordan har du lastet opp informasjon? (ved hjelp av mobil-kamera, digital-kamera eller skanner)?
- Hvor mange dokumenter har du lagret?
- Hvilke kategorier har du brukt?
- Prober: hvordan opplevde du at de forhåndssatte kategoriene passet for deg?
- Har du brukt delings-funksjonaliteten? (hvor ofte, med hvem)
- Har du satt en tidsbegrensning på delingen av informasjon?
- Har du brukt muligheten til å skjule informasjon (som du ikke vil dele)?
- Feil og problemer
- Har du opplevd feilfunksjon eller problemer med systemet? Beskriv hva du gjorde (eller forsøkte å gjøre) når disse oppstod

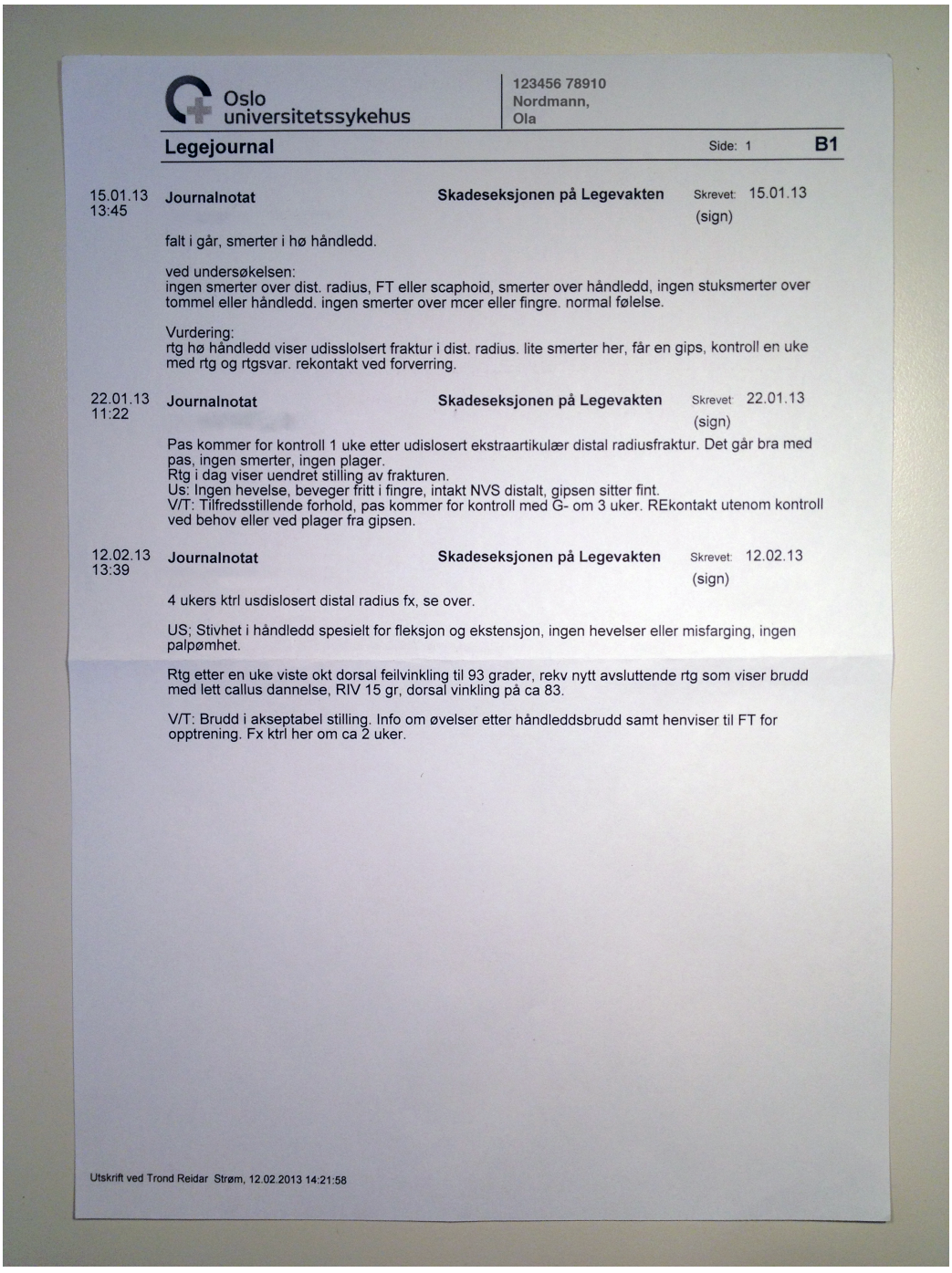
Ønsker og forslag til videreutvikling

- Hvilke andre funksjoner kunne du tenke deg fantes?

Appendix B

Example medical document

Next page.



Oslo universitetssykehus

123456 78910
Nordmann,
Ola

Legejournal Side: 1 **B1**

15.01.13 13:45 **Journalnotat** **Skadeseksjonen på Legevakten** Skrevet: 15.01.13 (sign)

falt i går, smerter i hø håndledd.

ved undersøkelsen:
ingen smerter over dist. radius, FT eller scaphoid, smerter over håndledd, ingen stuksmerter over tommel eller håndledd. ingen smerter over mcer eller fingre. normal følelse.

Vurdering:
rtg hø håndledd viser udisslolsert fraktur i dist. radius. lite smerter her, får en gips, kontroll en uke med rtg og rtgsvar. rekontakt ved forverring.

22.01.13 11:22 **Journalnotat** **Skadeseksjonen på Legevakten** Skrevet: 22.01.13 (sign)

Pas kommer for kontroll 1 uke etter udislosert ekstraartikulær distal radiusfraktur. Det går bra med pas, ingen smerter, ingen plager.
Rtg i dag viser uendret stilling av frakturen.
Us: Ingen hevelse, beveger fritt i fingre, intakt NVS distalt, gipsen sitter fint.
V/T: Tilfredsstillende forhold, pas kommer for kontroll med G- om 3 uker. REkontakt utenom kontroll ved behov eller ved plager fra gipsen.

12.02.13 13:39 **Journalnotat** **Skadeseksjonen på Legevakten** Skrevet: 12.02.13 (sign)

4 ukers ktrl usdislosert distal radius fx, se over.

US; Stivhet i håndledd spesielt for fleksjon og ekstensjon, ingen hevelser eller misfarging, ingen palpømhet.

Rtg etter en uke viste okt dorsal feilvinkling til 93 grader, rekv nytt avsluttende rtg som viser brudd med lett callus dannelse, RIV 15 gr, dorsal vinkling på ca 83.

V/T: Brudd i akseptabel stilling. Info om øvelser etter håndleddsbrudd samt henviser til FT for opptrening. Fx ktrl her om ca 2 uker.

Utskrift ved Trond Reidar Strøm, 12.02.2013 14:21:58

Figure B.1: Example medical document used during testing

Appendix C

Interview guide for general practitioner

- Om konseptet

  Gi en konsis demonstrasjon av systemet

- Innsamling av data

  Hva tenker du om at pasienter skal ta digitale kopier av utskrifter fra journal, prøvesvar, etc?

  Probe: Ser du noen utfordringer med at pasienter tar i bruk papirutskrifter på denne måten?

- Organisering av data

  Det er 5 kategorier i systemet som ikke kan endres. Disse ble foreslått av en annen lege. Hva synes du om kategoriene, og hvordan er det å orientere seg i de?

- Anvendelse av data

  Det er to hovedformål med min helsebok. Den ene er å undersøke om metodene vi foreslår skaper et mer aktivt forhold til egen helse gjennom synliggjøring. Det andre er å alltid ha sin helsedata for hånden slik at den kan tas med til konsultasjoner, eller deles med helsepersonell digitalt.

  Hvordan tror du Min Helsebok legger til rette for eller motarbeider disse målene?

- Underspørsmål:

  Hva synes du om deling basert på HPR og engangskoder?

- Til slutt

  Gitt at du ønsker å bruke dette systemet, ville du brukt det kun i rollen som lege, eller også i rollen som pasient? Dersom både og; ville du benyttet du e-postadresser for å opprette 2 konti?

- Annet

  Har du noen andre spørsmål eller kommentarer?